

**LITERATURE, THE ARTS, AND MEDICINE****Speaking of HIV/AIDS: Some Reflections on the Local Faces of the Epidemic**

David L. Clark, Ph.D.

Anna G. Joong, B.Sc.

Recent reports from the Joint United Nations Programme on HIV/AIDS (UNAIDS) suggest that the total number of HIV/AIDS cases worldwide, especially those in India, China, and Africa, may be significantly lower than previously estimated. Like the advances that are continually being made in understanding the nature of HIV and the treatment of HIV disease, these revised figures can only be good news, but of course the danger is that they will obscure the irreducible fact that the planet faces a pandemic whose dreadful consequences for individuals and for entire communities could hardly be over-estimated. If an efficacious HIV vaccine were developed tomorrow, it would not take away from the brute reality that tens of millions of men, women, and children suffer extraordinary hardships under the impact of HIV/AIDS across the globe, especially where poverty is the greatest. Nor would it make up for the incalculable losses that HIV/AIDS has left in its wake as the epidemic enters its third decade. For every success story in the treatment and prevention of the disease, there are thousands of other stories in the developing world whose outcome are much less happy.

Our cluster of short essays on the subject of HIV/AIDS brings the question closer to home, to remind readers that, while the unfolding disaster and heroic efforts in places like sub-Saharan Africa remain a top priority – worthy of our undivided attention and concerted action – HIV continues to be a pressing problem in North America and indeed in Hamilton, site of McMaster University's Michael G. DeGroote School of Medicine. Although the history and future of HIV/AIDS in North America is strikingly different than that of other regions in the world, it remains a medical

and cultural phenomenon that affects the lives of patients and care-givers in profound ways. Recent evidence shows that HIV infections are rising again in communities that have been disproportionately affected in the past, an up-tick that, among other things, underlines how AIDS education must change as the epidemic changes.

Those who are HIV positive (+) in cities like Hamilton continue to struggle with the social, physiological, and psychological consequences of their serostatus. Physicians never cease facing the challenges of treating an illness that is complexly caught up in patterns of behavior and questions of identity, and that runs up against the limits of existing science.

Our objective was to offer two HIV+ individuals, and a Canadian physician with considerable experience treating HIV disease in the Hamilton area, a place to reflect upon the nature of the illness, and to speak to the ways in which it has shaped and continues to shape their sense of themselves. Dr. S.M. Barber, Dr. Dale Guenter, and Mr. Peter Horner graciously share with us their remarks, in the form of individual autobiographical columns. The questions that our columnists ask are at once simple and complex: What does HIV look like, as it were, on the ground and locally? What has it meant to have come of age, professionally and personally, in the time of HIV/AIDS? We find their candid and thoughtful responses to be uncommonly helpful, so much so that they formed the occasion for David L. Clark to reflect upon the different faces of the epidemic in its local context. We conclude this – for us, inaugural – edition of "Literature, the Arts, and Medicine" with that discussion. †

## LITERATURE, THE ARTS, AND MEDICINE

### Addressing HIV

S.M. Barber, Ph.D.

On several occasions over the last few years, at the invitation of instructors in the Health Studies Program and in the Department of English and Cultural Studies, I have conducted seminars at McMaster on what it can mean to live with HIV. What is it that I hope to achieve when speaking to university students about my HIV history? Before I reply to this question I should note that although I am a teacher of philosophy and literature, in my classrooms my efforts are not directed toward offering any such account of myself and of my relationship with HIV. There, rather, I prepare students to think critically, using the rigor and capaciousness of literature and philosophy as a model. It is, at root, a form of training in how to sustain a questioning attitude towards everything that matters, whether inside or outside the university. Specifically, the goal is to help students tarry with difficulty, and thus to resist the temptation too quickly to resolve questions and problems that are much better left open-ended, not in spite but because of their demanding otherness. Sometimes the answer to a question lies in learning how to keep a question open as a question, even if that experience feels alienating, risky, and arduous.

This effort certainly continues in those classrooms in which I openly carry an identity card—that is, as an “HIV+ person”—although there it takes different forms. For in those classrooms, I arrive as an object of difficult knowledge and as something more than simply an object of knowledge. A part of who I am is what my students are studying, to be sure. But my goal is to be more than that, more than one more piece of the HIV curriculum. As I travel from one teaching situation to the other, I am turned upside down: in my own “regular” classrooms, where my role is “teacher,” I hope to teach students not only to know things, but, more important, to come to the realization that not everything can or should be treated as knowable—that is, quantifiable, calculable, and grasped as such. In those classrooms in which I speak as a person with HIV, however, I arrive as that unknown and unknowable other, hoping to be heard and engaged precisely because part of what is important about

me cannot be reduced to a question whose answer might simply appear on a final examination, no more than as a paragraph in a case history or a line of data in a lab report.

One of the things that I hope to bring to the classroom is the ways in which my own philosophical and literary education and my life with HIV came to speak to each other, and how that still unfolding conversation radically changed the ways that I understood and related to myself. Crucial to this transformation was the impact of the influential French cultural theorist and philosopher Michel Foucault. I began to study his work shortly before happening upon HIV, but it was with the diagnosis that I became a close and needful reader of his writings. After the diagnosis almost two decades ago, and after the loss of my friend to AIDS, I felt (as many of us diagnosed, though not all, in those days, did) that there could be no response to the disease, that it was a cruel caricature of what in us can respond. I mean psychically respond, not politically, because on that front I saw all around me the burgeoning activities of AIDS Action Now! and Act Up! As was ultimately to be recognized, Foucault played no small part in inspiring the practices of these new, politically creative collectives. Importantly for my self, though, it was Foucault who proved psychically crucial—not only as an intellectual I deeply admired and who had himself lived with HIV and died of AIDS, but also as someone who made it possible, within a deeply normative society, to imagine and to practice brand new ways of living with oneself...and thus with others, including the other who is always also oneself. The ambition of what Foucault wisely called “the care of the self” is not to make oneself “whole,” much less to return oneself to a former imagined coherence or even “health,” but rather the opposite: to reinvent oneself and to commit to living as if one really were a work in progress, never to be completed and in fact always turning away from the impulse to be complete. Such a practice amounts to a defiant challenge to the modern obligation to identify as one thing or another, and somehow to know oneself as such. Foucault saw the ongoing work of the care of the self as exciting, enabling, and above all as ethical, as evi-

dence of an abiding concern for and with others. That labour begins for him, as it does for me after having been taught by him, with learning to be productively at odds with one's self, and with the social forces that forcefully determine what and who we are. We are not or not only those things, and we can be many more things than we are told we can be. Somehow living with HIV and my philosophical education combined in subtle ways to teach me this lesson as never before, and it is a lesson I hope to introduce to others, my students especially.

So my reticence, in certain circumstances, to "come out" to my students as HIV+ is due neither to fear nor to self-loathing. My reticence in those classrooms is actually a chosen form of resistance: the point is precisely not to declare oneself as an easily known and knowable identity, a public announcement that gay men and HIV+ persons are strongly and repeatedly told they must do. What I hope to challenge – not only in my classrooms but in my life as well – are the forces that shape our identities, and that in fact mistakenly make "identity" the chief means of understanding each other. There are quite other ways of living with oneself and with others, ways that are more creative, supple, and responsive to the heat and dust of life; this is what Foucault helped me understand, this is what HIV made real to me.

If initially my diagnosis seemed to me a death-sentence, queerly enough it became that which compelled me to live and to live differently – not "to amend my ways" according to some morality but instead because I came to hear the diagnosis as a call from an Other, an invitation that was, and is, also an obligation to take my life as an object of care. Perhaps my students will also hear this summons, each in their own way, out of the open-ended project that is their

own life, each with its own challenges and difficulties, its own hopes, fears, and desires. I expect my need for a new form of understanding myself had from the start to do with the fact that when I was told I had HIV, I found the phrase a dispiritingly alienating one. I still do. I no more own HIV than it owns me. I no more possess HIV than it possesses me. I live with HIV. I mean "live" in its strongest sense—that is, quickened and troubled by the knowledge that nothing is set in stone, that there is always more to know, more work to do...and that all the things that I am – teacher and friend, citizen and student, lover and thinker, to name but a few – are part of that work.

When I speak to university students about my history of HIV, then, it is this history of relationality—with the self, with otherness, both inextricably interwoven—that I hope to convey. It is not as a confession that my history lesson unfolds, since that would assume a sovereign self, a moral code, and a stable, coherent knowledge, when, in fact, the ethical relationship of the self to the self, and of the self to HIV as other, is profoundly, happily, unstable and unpredictable, no less than is the knowledge by means of which one establishes the relationship. For my students, I hope to exemplify the possibility of just such an unfinished care of the self, not with the end of inspiring them, but rather to underline the importance of tarrying with that which is utterly unique about each person's relationship to this other that is HIV. As I speak with and listen to those others who are students, I like to hear them respond to questions that are there because of HIV, the illness with which I live, yet not explicitly posed by me: What is it to learn? What is it to live? †

#### **Author Biography**

**Dr. S.M. Barber** is Associate Professor in the Department of English at the University of Rhode Island. Before joining the faculty at U.R.I., he was a Social Sciences and Humanities Research Council of Canada Post-Doctoral Fellow in the Department of English at Duke University. Dr. Barber's research focuses on queer theory and critical practice, and on the relationships between contemporary French philosophy and British modernist literature. He is the co-editor of *Regarding Sedgwick: Queer Culture and Critical Theory*.

**LITERATURE, THE ARTS, AND MEDICINE****Me and HIV: Musings of a Physician**

Dale Guenter, MD

People with HIV are treading a path that I have never had to walk. Their world has often been shattered to pieces - physically, socially and spiritually. In an instant their lives have gone from making some sense to making no sense at all. From all of this, with what is left, they have no choice but to begin to rebuild. This is something bigger than most of us have ever had to go through. But then again, it is something all of us are going through all the time - having our world shaken in some way that changes who we think we are, what our lives will be, and how we make sense of it all.

I recall vividly the early days of the AIDS epidemic. At the time, enrolled in undergraduate studies in a Canadian university, and just beginning to grapple with my own sexuality, the news of gay men dying of some unknown infectious agent, which then became known as AIDS, and then finally as the HIV virus, felt at once too far away and abstract to stare at and yet too big to ignore. It became difficult to talk about sex without talking about AIDS, and new words were quickly becoming entrenched in everyday language. For a young man seeking a sexual identity, sex and disease became inseparable, deeply personal and altogether confusing.

Later on, in my days of medical training, I did my best to avoid being involved with people with HIV. I did not understand this fact well enough to have been able to speak it, but I know now that subconsciously I wanted to be as far away from them as possible. It wasn't exactly their disease I feared; I wasn't scared of getting infected myself. No doubt I found the depth of their suffering, the weight of their need, left me feeling overwhelmed and incompetent. But this is not what I was running from. Rather, I was more afraid of what it might mean to be associated with this disease, with these people, and what others might think or assume about me. These were the early and uncertain days of AIDS.

My own attitude was reflected back to me when, after completing several clinical rotations as a medical student in which my performance was reviewed quite positively, I received a rather negative review from the doctor who was leading AIDS care in this organization. He pointed out that I

seemed disinterested in HIV medicine, and that I had made little effort to learn about the disease or the patients to whom I had been assigned. This reflection was tough to disregard. From this training, I chose to work as a family doctor in an inner city clinic that served homeless people. I was a middle class boy who had never known the hard life. I needed to know what this other side of the world was all about and I needed to feel that I could do something to bridge the enormous gap. What I had not counted on were the people with HIV who came to see me and ask if I could provide their care since they had no interest in attending the HIV specialty clinic at the hospital. Presented with this challenge, I had to decide whether to rise to it or to run away. I chose to dive in, and finally began to face straight on the thing I had worked so hard to avoid. At about the same time, people in my personal life began to get sick, and this was even more impossible to ignore.

HIV quickly became my most important teacher, and I expect it will remain so for years to come. I learned that suffering has dimensions that go so much deeper than physical pain, that a society and a culture provide the rules for how people will be affected by a disease, and that healing can happen even if a person is dying, even if there is no hope of cure. I learned that the medical profession thinks about disease in ways that are often not helpful to the people who live with it, that our science easily washes out the most important colours and textures that need attending, and that my profession finds it difficult to face what needs facing in a suffering person when the science we work with is either inadequate or unwanted. HIV keeps teaching me what healing means, both for others and for myself, a lesson for which I will be forever indebted to this scourge. HIV has taken much from me, but as all of the great philosophers have noted, such loss also comes with many gains.

This epidemic has changed dramatically since its earliest days, and with change there are new lessons we need to learn about healing. Yes, we do need to keep striving for cures, for vaccines, for technological breakthroughs. It is our undeniable human "race." But honestly, this is the mundane work of medicine. We have some idea that longer and less disease-

ridden lives are more worth living, but alas, this idea is difficult to substantiate. More than anything we have to be attentive to what helps us to heal, rather than cure, when we inevitably hit a hard turn we had not expected.

For people with HIV who live in Canada, today's challenge is how to make life worth living when neither cure nor death is likely in the near future. Living year after year surrounded by stigma, with weakness, with uncertainty, without employment, or in pain is a hard road. Today's challenge for people who work with HIV issues is to get beyond being angry. Anger is the energy that has, justifiably, driven the response to HIV for more than twenty years, and with great

effect. But important work like eliminating stigma needs to continue and the culture of anger is turning from waking people up to alienating those we need working with us. It is also wearing down those working in the field. We need a new response. Finally, today's challenge for our planet is to take care of the most disadvantaged in order to take care of ourselves. Entire countries are being wiped out by this epidemic, and the answer will be not in a vaccine, but in our ability to narrow the gap between we who have and those who do not. The answer will be about justice and not about science. †

#### Author Biography

**Dr. Dale Guenter** is Associate Professor in the Department of Family Medicine at McMaster University, where he is also Associate Member of the Department of Clinical Epidemiology and Biostatistics. He practices HIV primary care at McMaster Family Practice, teaches in the undergraduate medical and family medicine residency programs, and works on research and programs related to HIV health services for the province of Ontario.

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## LITERATURE, THE ARTS, AND MEDICINE

### Discussion

David L. Clark, Ph.D.

The first of our columnists, S.M. Barber, is a Canadian born academic living and working in the United States who has taught seminars on the subject of living with HIV at McMaster for many years. Sharing his own long-time experience with HIV while also discussing the larger social issues associated with the history of the epidemic in a North American context, Barber regularly faces classes filled with undergraduate students who, by their own admission, have never before knowingly met someone with HIV (and who, perhaps more strikingly, often assume that no one in their classes is HIV+). Barber's unusual frankness and rigour ensures that these classroom encounters are illuminating and in some case unsettling for students, whose knowledge about HIV can now be tested on the pulses of a person for whom the subject is more than curricular. Barber tells us that he has himself been transformed by these seminars because they have given him an opportunity to consider his ongoing and always changing relationship with his HIV. His contribution to MUMJ is but one more step in that onerous labour of self-examination—a palpation of the mind and body, if you will, to which Barber has committed himself since testing positive some years ago. It is worth emphasizing that Barber chose to make this column, along with his classes at McMaster, the first occasion in which he has discussed his history with the virus outside of his health-care providers and his American-based support group. Needless to say, speaking publically about HIV is not without a host of complications, reminding us that HIV/AIDS remains a uniquely fraught social phenomenon as much as it is a medical one.

Yet Barber is careful to insist that his decision to speak in these highly selective venues was not negatively the expression of fear, much less shame, but instead strategic in nature. Not speaking to a wider public has, over the long course of living with HIV, paradoxically become a way to say something even more important; namely, that self-identifying as HIV+, like all acts of identification (“queer,” “woman,” “MSM,” to name three others), assumes that “identity” is the single most important way of understanding oneself and another. But is that in fact the case or always the case? The

processes by which a human being is identified and “known” remain an important part of making social existence meaningful, but an enormous amount of humanities scholarship has demonstrated since the early 1980s that these acts are imbued with power, and thus can be normative as much as they are descriptive. “Identity” is a topic that must be handled with great care: the advent of HIV/AIDS has made that lesson pressing as never before.

For this reason, Barber suggests, knowledge of his HIV+ status hardly begins to describe who he is or has been or will be in the future. HIV isn't for him a kind of passport of the self, to be given up at the request of the authorities. Declaring oneself to be HIV+ isn't as explanatory and self-consolidating as it is sometimes assumed to be; it doesn't make something essential about Barber transparently available to his listeners, much less to himself. It is instead a provocation to thought and ethical action, best understood as part of a much larger process of self-understanding that deliberately avoids the pitfalls of too hastily identifying and self-identifying. This complicatedly resistant and querying relationship with HIV, this insistence on making HIV the occasion for a radically new understanding of the self, has important philosophical precedents. As Barber writes, it was his great fortune to have grown up with the work of Michel Foucault, the widely influential social theorist who died of AIDS related complications in 1984, and whose late work is the intellectual force behind the emergence of the queer activism in which Barber has been involved for almost twenty years. As it happens, Foucault's work became a principle subject of Barber's research, but that is not the only way in which the French thinker plays a role in his life. From him, Barber also learned the importance of what Foucault calls “care of the self,” the classically inspired phrase he uses to describe a way of being in the world that emphasizes the contingent and self-devised nature of human existence. One must make oneself a kind of “practice,” Foucault argues, rather than let others tell you who you are once and for all. If being HIV+ means anything, Barber insists, it means working at negotiating and renegotiating its personal and social meanings, and thus living with the virus as if it were

a troublesome, demanding, and finally unknowable fellow traveler. About living with HIV, nothing is certain; as Barber suggests, learning to tarry with that incertitude is the difficult lesson that makes students of us all.

A great part of Barber's allergy to the very notion of identity is no doubt activated by the somber fact that it has often been put into the service of the worst stigmatization of HIV/AIDS. That HIV/AIDS has disproportionately affected gay communities in North America has often been used as an alibi to connect it fatefully to queer life, i.e. to claim, against all evidence, that it is primarily a "gay" disease. I recall that only a few years ago, some first year students I taught remained openly incredulous when they were told that heterosexual intercourse was the chief mode of the transmission of HIV in the world. Sometimes it seems as if more than two decades of AIDS education has yet to teach a basic lesson: the transmission of the virus has everything to do with practices, not identities, and thus with what you do rather than who you are. Teaching HIV remains a challenge, but our columnists put to us that the most eventful lessons continue to be the ones that the virus itself offers. The story told in Dale Guenter's column vividly makes the point. Guenter currently practices HIV primary care at the McMaster Family Practice, but his relationship with the virus goes back to the time before he became a physician. Indeed, the emergence of HIV in North America—a period of considerable confusion and half-knowledge about the virus—coincided exactly with his days as an undergraduate student, when he struggled to discern the contours of his own sexuality. This was an inauspicious coincidence, to say the least, for it seemed at the time to personalize the epidemic in the worst possible way, i.e., by connecting sexual pleasure with disease, and non-normative desire with death.

Although Guenter does not say so, this was an association that was undoubtedly fueled by a longstanding social prejudice that has, since the nineteenth century, unjustly associated homosexuality with illness and self-destructiveness, a prejudice that found an unexpected and virulent new life in the age of AIDS. With admirable frankness, Guenter suggests that his initial and intensely over-determined encounter with HIV/AIDS, at once vexing and difficult for him personally, cast a shadow on his early development as a medical professional. While in training he found himself keeping an almost unconscious distance from people with HIV, not because he was concerned about becoming infected, or because they represented patients whose enormous need for help felt understandably overwhelming for a new physician at a time when the treatment for HIV wasn't nearly at the place that it is now. As Guenter explains, his reluctance to involve himself more fully with the lives and deaths of persons with HIV symptomatically expressed an altogether different discomfort in him; almost without knowing it, he was unsettled by the chance that associating with AIDS patients

might implicate him personally, and say something about himself that he wasn't altogether sure he wanted said or known by others. It was indeed not infection that Guenter feared, but an altogether different sort of contamination; in spite of himself, the young physician felt out of control of the meanings that others would attach to him merely because of his working proximity to HIV and HIV disease. In the early days of HIV/AIDS, Guenter's experience underscores, the social and cultural context of the epidemic that played a significant role in how it was understood, experienced, and treated, and not only by HIV+ individuals. It still does. A disinterested demeanor undoubtedly plays a key role in the practice of medicine, but Guenter's remarks remind us that physicians are finally like everyone else, fully embedded in the culture in which they practice, and thus shaped, for better and for worse, by the societal expectations and assumptions that are always at work there but especially at the nexus of identity and sexuality.

I say "shaped" by these forces, but of course there is nothing preventing a mindful physician (or, for that matter, an equipment mechanic or English professor, the professions of our two other columnists) from responding in turn to the environment in which he or she lives and works, or from radically retooling his or her assumptions about illness and identity. Guenter's experience forcefully proves the point. Although he may once have turned away from HIV, HIV had a strange way of catching up with him. Practicing in an inner city clinic serving an HIV+ population, Guenter began to meet and reflect upon his fears, compelled by the implacable needs of his patients to revise his assumptions about the ways in which his life and work were unavoidably intertwined in the age of AIDS. After Barber, and in memory of Michel Foucault, we would call this transformation a "practice of the self". What did Guenter learn from HIV – or rather, what sorts of things is it teaching him still? The short answer would be nothing short of everything, so far-reaching is the still unfolding lesson at hand. For as Guenter suggests, working with his patients has subtly and utterly altered his sense of himself as a physician, at once clarifying and complicating his role as a health-care provider for those for whom HIV/AIDS is so very much more than an infection and a syndrome.

To be sure, HIV/AIDS is a biomedical phenomenon, but it is also a deeply affecting and globally important crisis of meaning (or "an epidemic of signification", to recall a useful phrase from Paula Treichler), a uniquely wrenching moment in human history that challenges the very basis of our understanding of what it means to live and to die, to be ill and to care for others, a moment, moreover, that brings out as never before – for those with the eyes to see it – how social and cultural inequalities largely account for the shape and scope of the epidemic world-wide. These inequalities and differences call out for critical understanding and above

all action, both near and far. Like the environmental catastrophes also haunting our times, HIV/AIDS makes a clear cut distinction between the two universes – the local and the global – ultimately untenable. “African” HIV/AIDS is different from HIV/AIDS in North America, but we must always be wary that in emphasizing that difference we don’t forget that it remains our unwavering obligation to do something about it both here and elsewhere – not tomorrow but today, and as a promise made in earnest of tomorrow. HIV is his “most important teacher”, Guenter tells us, one of whose greatest lessons has been that healing others means not curing a patient but bearing witness to his or her irreducible singularity, as exhausting, unpredictable, and unteachable as that work necessarily is. As Dr. Guenter suggests, we must seek to do justice to the epidemic as well as know what it is.

Peter Horner, our final contributor, concludes his column by telling us that he has AIDS, and that piece of information means that he is on a path that is different in important ways from the one that Barber walks. The distinction between being HIV+ and having AIDS is of course incomparably relevant for a host of reasons – personal, social, and medical. Too little attention is sometimes paid to the difference; there are individuals, each of whom should know better, given the long history of AIDS education, who continue to conflate the two things. We don’t often hear the suggestion, as we do in Horner’s column, that it is also possible to pay too much attention to the distinction. We see this counterintuitive hint perhaps most clearly in the ironic post-script that he adds to the biographical statement accompanying his contribution: “Oh, and he has AIDS”. A mock throwaway whose third-person voice quite deliberately puts some distance between himself and his AIDS, Horner’s remark could be paraphrased as saying “I’m not going to understate the significance of my current health, but I refuse to let it be the only thing, much less the first thing, that you know or think about me.”. Strictly speaking, AIDS could never simply be an after-thought, something about oneself or about another that you could almost forget and then remember to add in the nick of time. But it is helpful momentarily to stage AIDS as if that were the case, as Horner does in that little addendum: knowing that he has AIDS is critical, yes, if for no other reason than it lets readers understand something about the complicated place from which he speaks. But there are so many other things that are also important about the illness, and Horner wants to ensure that we know that too. So he defers saying that he has AIDS until the end of his remarks, not to evade the question but to call for more complicated and capacious queries from his readers. As we see in different ways in the other columns gathered here, HIV can make people – regardless of their serostatus – acutely aware of their surroundings, and particularly vigilant about how HIV may be understood or misunderstood by others. So it is that

Horner does not begin his column by telling us about his current health status, no more than Barber has simply disclosed at every opportunity that he is HIV+. Each is careful to practice a kind of circumspection about what they say and how they say it, deliberately resisting the imperative simply to disclose, and in doing so each columnist models for others what it means to be at once respectful and thoughtful in the neighborhood of HIV.

“This is positive”, we might say of that particular lesson, remembering the pointed turn of phrase that paces the narrative of Horner’s entire column. Far from a mere slogan, it is a declaration that demands that we sit up and listen, as if hearing a bell tolling in the night. But it is also a promise, and thus a declaration of hope made in earnest of a healthier future, a future less marred by the cruelties and missteps that Horner recalls, and that he asks us not to forget when we tell the story of this epidemic going forward. Given what Horner relays us in his narrative, the fact that there are “positive” signs in the midst of an epidemic is nothing short of miraculous – except to describe it thus would be to elide the suffering, sacrifices, and plain hard work that has brought us by fits and starts to the point that a man like Horner can say “This is positive” and mean it. As with Guenter and Barber, the emphasis is on how HIV has played the role of teacher, but as Horner makes pointedly clear, the lessons learned are not so much naively uplifting and ameliorative as cautiously hopeful and enduringly arduous in nature. One thing Horner is not inclined to do is to sentimentalize HIV as an untrammelled font of wisdom. “Being positive” does not mean here what it can sometimes mean elsewhere, i.e. possessing or being possessed by a cheerful outlook on life, as if a change in one’s attitude towards a problem solved everything. We get no Hallmark card platitudes about HIV/AIDS from Horner, no blithe clichés which would only mean fleeing the realities of illness rather than seeking a way to thrive amid its interminable difficulties. What HIV teaches, and what societal changes have been wrought by AIDS, have been far too hard-won to be treated with anything but this kind of frankness. For as Horner tells us, whatever the future holds, HIV/AIDS has meant surviving a legacy of searing losses: his husband and helpmeet, his livelihood, and his home have all been taken from him; he has lost friends and acquaintances to HIV disease, either to illness or to the irrational fears and misunderstandings with which the epidemic is uniquely burdened. He suffered isolation and injustices both before and after he made his condition known to others. Horner makes the memory of these deprivations feel uncommonly real and pressing to the reader, reminding us that their deleterious effects remain not only woven into the very fabric of his life, but form an ever-present backdrop to the “positives” that he discovers in the midst of the epidemic and describes for us. Grabbing hold of those “positives” is undoubtedly a move in the right direction, but Horner’s



column also ensures that we remember how terribly dear the costs have been in getting us to that hopeful place. In other words, in Horner's experienced hands, the "positives" do not balance out – much less cancel – the "negatives". HIV/AIDS isn't available to that sort of calculus because the losses swirling in its wake remain unaccountable and without the possibility of restitution, an important lesson well worth recalling when we hear talk of an HIV vaccine being around the corner or news of revised downward estimates of the world's HIV/AIDS numbers. Horner is not about balancing the books, or reassuring us that all will be well, but about finding a way to live life and to live, as he says, for the rest of his life.

Perhaps this is what it means to heal, as Guenter says, even if for now a cure seems improbable. Amid these losses, Horner insists that there are "positives," not in spite but precisely because of the sorts of "negatives" that he describes enduring in his own life. Because "negative" remains a grossly inadequate word to describe the death of a loved one to AIDS, "positive" is a word that Horner uses with

implicit caution and only in a larger historical context of love and loss going back twenty-five years. But use it he does, since there is no gainsaying the ways in which the epidemic has spawned a range of activist interventions and politicized movements that are now directly responsible for increased awareness about HIV/AIDS, legislative changes, and better treatment options, as well as the creation of networks of support-groups and service organizations. And there is still a great deal of work to be done. These are "positive" signs, Horner says several times, affirming a reality that should indeed be affirmed, and that is affirmed in a particularly powerful manner by those who have been on the ground, so to speak, during the time that HIV has been with us, the time in which, in consequentially different ways, we have all lived with AIDS. The fact these signs require repeated avowals also puts to us that the avowal itself functions as a kind of talisman or incantation, spoken aloud as if to ward off, for a moment, the heart-break that it also remembers.

We thank our contributors for their candour and courage, and for having taught us so much. †

#### **Author Biographies**

**David L. Clark** teaches students of that generation. He is Professor in the Department of English and Cultural Studies and Associate Member of the Health Studies Program at McMaster University. He has taught courses and supervised graduate research on the social and cultural aspects of HIV/AIDS for many years. His Wisconsin Public Radio interview on representing HIV/AIDS can be found at <http://www.humanities.mcmaster.ca/~dclark/index.html>.

**Anna G. Joong** is a medical student at McMaster University who recently traveled to Uganda to see first-hand how HIV/AIDS is treated there. She is a member of the first generation of men and women who have never lived in a world without HIV/AIDS.