

Ecos: ¿A quiénes no estás escuchando?

Echoes: Who aren't you listening to?



Ecos: ¿A quiénes no estás escuchando?

Echoes: Who aren't you listening to?

cepa

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Introduction. *Who Writes About Us?*

This work is the result of a collaboration between **cepa**, a local community of HIV-positive people in Tlaxcala, Mexico, and the collective, What Would an HIV Doula Do? (**WWHIVDD**), with the support of **Knowledge of AIDS**. Together, we have built a space where voices—multiple, complex, anonymous, visible—come together to challenge the power structures that have historically decided who gets to speak about HIV, how it is spoken about, and for what purpose.

Naming HIV demands, urgently and inevitably, that we confront a colonial history. We have inherited a model where «*the Other*» is subjected to the scrutiny of Global North methodologies. We have suffered the cliché of the anthropologist traveling to the Global South to investigate from a supposedly sterile distance, aiming to report on that «*other*» population which, in their eyes, lacks the methodological validation of white supremacy¹. Faced with the academic illusion that research can—or should—be neutral and objective, this project embraces autoethnography as a political, socially just, and conscious act.

Traditional academia has forbidden marginalized populations from studying themselves, arguing that doing so would betray the ideals of such objectivity. However, we acknowledge our subjectivity and assert that it is necessary to collapse the extractivist hierarchy of «*researcher vs. researched*». Instead, we propose a reparative process of dialogue where both parties share the same circumstances. Here, the researcher is part of the community; they are an accomplice. Therefore, knowledge is not extracted to benefit an individual

author, but rather, that knowledge belongs entirely to the community. We do not seek to catalog facts or yield to the compulsion of creating fixed concepts, because we understand that nothing is an immovable structure. What we are doing here is a way of inhabiting uncertainty, a response that echoes the multiplicity of the world.

8 Inhabiting that multiplicity also implies questioning the language from which we construct and share our knowledge. For this reason, we knew from the beginning that *Ecos* had to be bilingual—Spanish and English—not only for the sake of access, but out of political conviction. Language is memory, identity, territory. In times when the global narrative around HIV remains dominated by English-speaking perspectives, reclaiming the right to tell our story in our own language, with our own nuances and accents, is a profoundly radical act. Because when we translate, we also transform. And when we converse in our mother tongue, we recognize ourselves.

Upon recognizing ourselves, a foundational question arises, one that our friend and artist Daniel Cortez Abreu posed to us from the very beginning: «*Who writes for us and about us?*» Answering this demanded that we think about how to stop being passive subjects of HIV-positive knowledge and venture into risky narratives. Since 2024, through the *Persiguiendo Metáforas* (Chasing Metaphors) program, we have attempted to reclaim writing—in its broadest sense—as a starting point to imagine how we wish to present ourselves to our peers in the near future.

Thus, the methodological genesis of this project organically divided into two moments. The first part of *Ecos* was born from an intimate and urgent dialogue among members and allies of cepa who live visibly with

their diagnosis. We firmly believe that bringing our experiences together, in our own voices, allows us to have a more raw and authentic conversation; one that does not seek comfort, but epistemic justice.

But understanding why we chose this dual process also requires looking inward: the majority of the people who attend cepa do not live visibly with their diagnosis. So, how do we create policies and practices to also include those who do not live publicly with the virus, without reducing them to mere subjects of study? The easy answer has always been anonymity. And yes, anonymity has been a necessary refuge, but it has also been a barrier: if we must always hide in order to participate, are we truly participating?

That is why, in the second part of the project, *Ecós* dares to problematize that comfortable solution. We gathered the people of cepa who do not live publicly with their diagnosis in a safe space to create texts and images that attempt to answer: Who are we? Without revealing what we do not wish to reveal. Here, anonymity takes on two dimensions: the first is to prevent risk and harm; the second, profoundly creative, consists of collapsing several people into a single persona, as a way of reclaiming and resignifying our collectivity. And yet, we are aware that in these exercises, there are parts that are left out—and that, in their own right, must remain left out. That opacity is also ours.

We want to close by thanking, from the bottom of our hearts, those who made this act of collective courage possible. To Jorge Bordello, whose sensitivity and leadership guided the folks in the creation of the images that accompany this publication. To Daniel Cortez Abreu, whose empathy and rigor coordinated the drafting of the texts for the second part, weaving words with respect and

depth. And, of course, to every person who left a mark on these pages—visible or anonymous—because without you, Ecos would not resonate.

Beto Pérez
Director of cepa

(1) When speaking of white supremacy in this text, we do not refer to extreme hate groups, but rather to whiteness constructed as a structural system of privilege that entraps both oppressors and the oppressed. Following Houria Bouteldja in *Whites, Jews and Us*, white supremacy must be understood as an epistemology: a system of thought through which the “white subject” perceives and orders the world. Drawing on philosopher Enrique Dussel, Bouteldja links the origins of this whiteness to Descartes’ formula, “I think, therefore I am,” which in reality conceals a “conquering ego” that assumes the role of God and positions itself at the center of the world-system. By secularizing divine attributes and bestowing them upon Western “Man,” reason itself becomes a “parable of the white man.” Thus, this epistemological supremacy operates by declaring itself as the absolute and the universal, while relegating all others—our bodies, our histories, our knowledges—to the peripheral or the particular.

PART I

***When Visibility is a Double-Board Game:
Conversations with Sara del Arco.***

By Daniel J. Cortez Abreu

Sara del Arco (Ceuta, 1992), like many of us, finds it hard to introduce herself, even though she is deeply aware of her position in the world and the complexity of the identity she inhabits. She prefers to start with what «*people can see*», to later add aspects that help break down prejudices. Thus, at first glance, she describes herself as an Afro-Spanish woman, mainly to remind us that, within Spanish territory, people tend to forget that Afro individuals are an inherent part of its origins. More formally, she defines herself as a mediator and sexual health educator, although, academically speaking, she is also a social and cultural anthropologist. Sara's voice, which breaks through with strength and conviction, serves as an invitation to think and to engage in an honest, critical, and situated dialogue. Through playfulness, she gifts us metaphors that allow us to understand a way of living with HIV, something she has embodied since birth. Sara belongs to a generation of children and youth who were born and raised with an HIV and AIDS diagnosis, and who have had to construct themselves as political subjects—despite being profoundly invisibilized—in order to reclaim their agency, their rights, and their place in the world. On this occasion, we held a video call to discuss the complexities of being visible while living with HIV.

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**Daniel J. Cortez Abreu* is a physician specializing in the health and social care of people living with HIV; he has also studied social and cultural anthropology.

Daniel Cortez (D). Do you think that today visibility is a choice, an imposition, or a necessity? How do you perceive it on a personal and professional level?

Sara del Arco (S). [Begins in a serious but relaxed tone] Today I perceive that visibility is a choice, and in fact, that's how it has to be. It was an imposition before because there was no other option, and circumstances led to it. Now I think we are in the realm of choice, and that is very positive [smiles]. And speaking specifically about people with HIV who are visible, at many times it is an overwhelming burden, or at least, many have felt that way at different stages of their lives. [Returns to a serious tone] I think this speaks volumes about how HIV is perceived in society, because when you become visible with another condition, it is not a burden, but a relief. Although generally, at the beginning, it can be overwhelming—due to all the information, the support groups, the people, and the many hands involved—eventually that weight disappears and it seems the path becomes smoother, right? But regarding HIV, it usually doesn't happen that way; the path has many ups and downs, walls, obstacles, labyrinths... Because on a social, administrative, institutional, identitarian, and collective level, if you don't navigate highly sensitized spaces, you simply don't perceive that support.

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(D). Building on what you're saying, I remember a politician in a roundtable discussion commenting that he didn't experience stigma for having a rheumatological disease, compared to what happens to us as people with HIV. There is a hollowing out of all that symbolic meaning when you disclose your serostatus, an act where stigma plays a central role. I also agree with you that this disclosure is now elective, although I think it equally depends on the context. At least in the Spanish State, it tends to be a choice linked to privileges regarding access to healthcare, but in other territories, it is different.

However, taking into account your life trajectory—since it differs from what people expect the image of a person with HIV to be—how have you experienced that visibility? Above all, regarding the fact of having been born and raised with HIV. What role has visibility played in that journey?

(S). [*Smiling broadly*] Totally agree, Dani. It's true that many times we speak from a tiny context or we just get caught up in the day-to-day. Thanks for bringing that up. It is true that it's a choice in the space and moment I find myself in right now, but for many people today, it continues to be an imposition. And here I'll link it to your question about my growing up, my childhood, and adolescence. Well, since it has been a part of me, it is a different experience, and I always explain it as if there were two societies, right? There were two worlds: two matches of two completely different games. Imagine that in one I am playing Parchís' [*Ludo/Parcheesi*], and in the other, chess. But I remain the same person in two different matches, with totally different people on each board who just have to be themselves; they don't have to be playing both games at the same time. I have always experienced it like this, and I use the example of these two games because one is very simple, colorful, and more family-oriented, and in that one, everything was much easier for me. That was the context in which people knew about my HIV, where the rules were constantly being adjusted or were flexible, so to speak. When people in my childhood environment knew about it, it was handled with great care—although I have a few anecdotes — especially because adults and professionals didn't put their profession first, but their humanity. Something that now, in the political times we live in, is being lost, and they even force you to lose it, right? To ensure that [*humanity*] is not the center; it's like they divide you, you have to be a robot and that's it, for work or whatever they deem necessary, you just have to follow numbers or guidelines. Then, when I went out into another part of society that

was ignorant about HIV, it was like playing a game of chess without really knowing the norms or the rules of the game. It was a matter of asking and learning, «*the knight can only move in an L-shape, and this other piece can go like this*». That's why I always say that, for me, navigating it has been a challenge and a game at the same time. Because when I left the more familiar part—that fun game—on the double-sided board, I then had to be in a game where there were only two positions: black and white. Suddenly, I could go from the family game to another where I was totally opposed to the other player; there was no middle ground. That's why I always choose these games to explain it, because that's how my experiences have been. In fact, all my activism dedicated to childhood and adolescence has always been about knowing which game I want to be in, how I want to move my board wherever I need it, and for it to be easy. It's true that during my adolescence—my rebellious phase—I tried to merge them. I would say, «*No! I want these two to be together! I want them to understand each other and for the players to move from one to the other*». But then it turned out that some players were totally opposed or confrontational and would say, «*No, no, that game doesn't interest us*», or they wanted nothing to do with it, or «*What are you talking about? We are somewhat above this*». And the thing is, socially, this happens with games: many people consider some of them to be very flat or even useless. But if we go to the core and ask ourselves, what is a game for? It serves to build community, not to make you feel elite. In fact, that happens with chess, where some people feel elite. There is a lot of advertising related to playing it and feeling smarter. But I encountered people who, when playing a match with me, were not smart at all; in fact, they were deeply ignorant regarding the familiar, and how flexible life could be, whether you have HIV or not. And that's how it has been.

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(D). I love everything you're sharing. Furthermore,

using a playful metaphor to understand these experiences is something I think we really need, and I believe it also reflects the construction of your personal identity based on the community work you do, beyond just having grown up with HIV. These are the metaphors we need to discover and explore. Building on this, I wanted to ask you about visibility and the testimonial approach: sometimes it seems to me like a strategy that exhausts itself and doesn't allow for other avenues—like comedy—to be explored, or that pushes collective narratives aside. Also, a few days ago, at a roundtable of the Ministry of Youth and Children, you were talking with other colleagues about how children with HIV had to become political subjects. From government institutions to the pharmaceutical industry, or even NGOs themselves, many have used visibility and personal testimony as a strategy to put a band-aid on unaddressed issues or institutional failures that do not provide real answers to the problems affecting us. I have the feeling that the construction of that political subject gets lost. Why do you think this happens? What could be other ways to approach that visibility without relying solely on personal testimony?

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(S). I think this happens for a very basic reason, and that is the economy. I mean, all progress has a «*B-side*»—or even a «*C-side*»—of an entire financial process and a structure that sustains it. This strikes a much deeper chord when it comes to people's health, because we are not talking about something unnecessary, but about a basic right like health. We are not talking about buying a car, a TV, or it being a luxury item—or about each person's ability to access different tiers of those products. Here we are talking, furthermore, about something that is not endemic, concentrated in a single town, but about a much larger and global issue at a population level, across ages, all social classes, ethnicities, etc. It also comes into play that this financial side—which is the biggest muscle,

one that has been very powerful when negotiating with administrations, from the pricing of medications down to the end user, the patients—has not invested in us. They haven't had the proactivity to include us in general, neither at a professional level nor in research. They really haven't wanted to allocate a portion of funds—as is done through certain grants or subsidies—towards the professionalization of people with HIV. They haven't invested in the user; instead, we are just customers, it's just that the Administration acts as an intermediary between us. When you go to a giant retail store of any of these big brands where you serve yourself as a customer, you have an intermediate negotiator—a professional who understands the components of this medication, for instance, who knows what's in the product and how it will affect you. At no point has that financier, that stakeholder, as we might say, invested in us. They have never truly defended us at the university level, nor have they genuinely supported us.

20 Not only has there been nothing for us because they have focused solely on profits and the financial side, but they have even gone so far as to negotiate with the Administration for the worse, to a negative degree regarding their connection with us. Therefore, I might have found myself taking two or four pills a day when I could be taking just one on average. Why? Because that is what's cheapest for the intermediary—the hospitals and doctors. So the moment this is allowed to happen, somehow, the relationships and ties surrounding me lose a bit of credibility. That's why sometimes I am so harsh in some of my communications: because, socially, we are treated like a patient with any other condition, but it turns out that we, patients with HIV, have had to be the foremost activists and advocates—often side by side with doctors—to fight and demand our rights. Perhaps they [*the doctors*] did it on a more administrative level, setting the scientific criteria, while we provided the lived experience, although this dynamic is breaking down in many countries. But returning to

the board: what has that done historically? It means that when you are in the chess match and they tell you, «*No, no, you don't know anything*», well, actually no. In reality, the HIV patient knows a lot, not only about their medication but about this entire trajectory and the negotiations, because rights had to be fought for. Especially taking into account that the pharmaceutical company has bargained hard, but not for our benefit at all.

(D). I completely agree. Our image is capitalized upon, and we, people with HIV, are considered «*passive*» patients: vessels for violence and power, without agency or voice. This leads me to think about how visibility has constructed a regime of representation in which a “visible” person must be someone who is medically adherent, maintains good lifestyle habits, is happy and grateful for their treatment, and is not overly confrontational. Ultimately, this leads to the stereotyping of what it means to be a person with HIV or what our «*face*» looks like. This even contradicts what global statistics show us, because, although the perceived face of a person with HIV is that of a white cis-gay man, the people truly most affected by the epidemic are Black cis-hetero women. However, I want to pivot to another point relatively related to the previous one. It seems to me that the message «*Undetectable = Untransmittable*» (U=U) leaves behind an identitarian footprint that revolves around a lab metric and the avoidance of being a vector of transmission —although, in a certain way, it has also allowed people to not be obligated to disclose their serostatus. I think a moral value has also been attached to the fact of living with HIV. Do you find this problematic? Do you think the U=U message has affected our visibility? How have you experienced it, taking your personal history into account?

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(S). I think U=U is a super necessary message, but you have to look at the marketing [*laughs*].

And this is a very personal opinion... To me, the fact that the marketing for this message is an equation complicates my life [*laughs again, then adopts a more serious tone*]. It feels alien to me. Not so much as a person who understands and is up to date on what is happening with my condition, but from the position of someone totally outside of this, I think it doesn't land the same way, no matter how you slice it. I mean, I think it's great, a totally necessary message; but asking people to solve an equation when people already don't like math... I don't know. I've always wondered about it because [*the emergence of $U=U$*] was a process that started when I was still in university. And although I understand it has a beautiful underlying meaning, it all goes back to the same thing: we have to dig deep to understand this reality. Advertising messages are the opposite; they are designed so you understand things at a glance. So it is a strategy I can support, but one I'm not entirely satisfied with because it requires solving an equation. Therefore, we are

22 the ones making it very complex ourselves. Sometimes I understand that we don't put all the information out there as a way to protect and take care of ourselves. But maybe we should communicate all the information in a beautiful and eye-catching way, just like that, raw: «*there are no more transmissions*». And maybe display it so that each word appears on screen and each one has its own emphasis; I think that would look much better, right? For example, as if someone were typing on a typewriter—in fact, there is already some advertising like that—and that would have much more impact. And then, to expand on the information, it would be like medication ads: «*consult your pharmacist*», «*consult your doctor*». But the information has to stop being encapsulated solely within our own circles in an attempt to protect ourselves. Well, I don't know, maybe it's because I belong to a generation—and also due to my personality—where I challenge, fight, and protest when I feel things aren't working. As you said earlier, when I was a child, children's voices in all

aspects were quieted and silenced, and now they are not. This is especially true thanks to those events regarding childhood we've already mentioned, organized by the State Coordinator [CESIDA²], the Ministry of Youth, and other entities. For many years we have been silenced, and we haven't felt that these messages and discourses belong to us. Why? Because we have lived other realities that, until now, even from within our own community, were not the ones being shared.

(D). Exactly, I think in a way they also get left out of the equation. And I agree that resorting to simple math to reduce a highly complex reality ultimately strips away its complexity when it becomes a logo solely intended to summarize or facilitate a message, which, in the end, falls short.

(S). And then there are many people who don't identify with it, because there are people with HIV in any context who, if on medication, the virus's activity radically drops and therefore it's not transmitted—perfect. But what about the people who don't have an undetectable viral load, yet won't transmit it? What do those people identify with? In our case [*referring to people born with HIV*], our immune system has been so affected and damaged that sometimes the virus doesn't rebound; and ultimately, you also have to consider that we go through a growth process where the immune system isn't fully formed yet. There are also people who are not undetectable, and not because of poor adherence. But honestly, even if you do have poor adherence, where does the dignity of the person go? I don't think we should throw stones at them or push them out of the equation, because there are many factors: maybe the medication is hard for them, maybe they don't like it, or maybe because taking medication simply sucks.

(D). Sometimes the medication simply doesn't work, and

that's it. What do we do then?

(S). Exactly [*she adds sharply*]. So when your body doesn't respond—as happens with other conditions—in the context of HIV, the person is blamed, or they aren't even factored into these equations or discourses, even when that person or their doctors have tried everything possible. And I repeat, in other situations, you are cared for, protected, helped, they look out for you; but when you have HIV, it's different. And here I would like to emphasize that, in this regard, age has not mattered. Even as children or adolescents, the person is blamed when what might actually be failing is the chemistry, or the damage the virus has caused to the body. I always ask the same question: who likes being sick? Because if anyone can tell me they enjoy being sick.

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(D). Well, even in psychiatrized individuals or those with some nosophobic behavior, when you really provide them with care and start working with them on what is happening, often their distress disappears. You realize that what they needed was an explanation or simply to be heard, because they didn't want to feel bad either. I think regarding what we are talking about, there is a very strong moral component to HIV. In the case of diabetic people who cannot achieve optimal blood glucose control, they might be judged and told that they don't know how to do things or don't want to take care of themselves, or whatever, but mainly because it has consequences for the individual's own health. But in the case of people with HIV, behind that moral judgment, there is not only a religious component but also an assumed dangerousness that we represent to society, or the financial burden we generate for public healthcare. So here, the stigma is magnified. Well, I think ultimately this leads us to think that U=U is an insufficient message. On the other hand, I think there is a certain ambiguity in the way we make

ourselves visible. That is, we can be visible depending on the context—with friends yes, but not at work, for example—as if it were a reversible state, returning to the closet in some cases. In the end, I think we are expected to maintain a consistency or homogeneity with the decisions we make, which are actually strategic. What is your opinion regarding visibility and that reversibility?

(S). [*Responds calmly*] Well, in the end, the act of becoming visible or wanting to share an experience you are having depends on the context and the trust you have with those people in those spaces, right? So it is very specific, and no one should be forced to be visible in one environment just because they are in another, or even within the same environment, but only with certain people in it. The thing is, you, me, or anyone else don't share the same things even within a close circle. You might not share the same thing with your mom as with your dad [*smiles*]. Maybe you come home wanting to tell something and you do it first with your mother because she is the first person who embraces you. And then, depending on how you shared it, how you assimilated it, and once your emotions have stabilized, then maybe you share it later with your dad, your siblings, or with any trusted person; and that also depends a bit on the topic, right? So, if our cultural dynamics and emotions work like that, why suddenly do I have to share everything in a public square? I have been visible since I was very young, especially in the news or public discourse, but on many occasions, I haven't been. Sometimes people have found out, and if they stay in my life, great; and if not, let them ask if they feel the need to. I also don't think that relationship has to change because of it, because we have already established a bond. And in the same space, there may be people who already knew beforehand because it came up in conversation, and in others, there will be people who are just finding out at that moment. If someone feels that things have to change, well, that's

it, I've understood that they don't have to stay in my life. But what is certainly true, what I never, ever suggest is that we should judge someone who has decided to be visible—for a while or during a good moment in their life—and then decides not to share it anymore—because motherhood or parenting comes along and at that moment they decide not to be in that space. That also seems perfect to me. Sometimes you have to rest, and I have ended up doing that too. Sometimes you have to take a break from socializing around HIV [*smiles mischievously*].

(D). Exactly, it seems that both visibility and HIV have to be the central axis of our identity or our way of existing, and that cannot be. Even identity itself is mutable; therefore, visibility can be too. This leads me to the next question: who is visibility for? For institutions, for society, or for people with HIV?

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(S). [*Looks down slightly and responds calmly*] Right now, I think that, generally, the people who have had no other option but to be visible have been so for science, for research, for community organizations, for protest, and for improvement and progress. That's why I said it had been imposed, because ultimately, those of us who became the face of it didn't even want to. But there is also a more media-driven visibility, the kind that only happens on designated awareness days and that's it, and maybe you never speak again to that journalist with whom you shared just a little time and who has no further interest in your life. I also protest against this, because it is very cold and it feels like I am reduced only to this. If I am contacted solely for the fact of having HIV, then that contact is not going to happen, because I am much more than HIV. If, on the contrary, you show more interest and what you are going to reflect about me is a more specific profile, perfect. In fact, I have raised awareness among some journalists from specific media outlets. Sometimes people I know

approach me and say, «*they asked me about this and this*», and when journalists write to me, they already have a preformed narrative about me, and I do not accept that. For me, there have to be minimum standards, so first we evaluate those minimums—and if I am doing well at that time—and if we both agree, then go ahead. If not, then they should consider doing it with someone else who agrees, or who is in the mood and has a similar experience. Whether from a scientific perspective—because, for example, many times scientific profiles are sought, like doctors who have never worked in the HIV field—if you haven't dealt with people with HIV, you won't have a clue. Sometimes, some researchers know the process or the basic cycle of the virus, but they won't have lived the evolution of the disease, and they might be highly trained in other conditions, but not in HIV, which can be totally different from what you know. So I think you have to ask those who are focused on HIV scientifically, whether in the first person or living in contact with our reality. From there, great. Now, I also advocate for people's visibility to be exactly as they want it and, above all, chosen. At first, I had a very disruptive or expressive visibility, and then I hid because I discovered how people could be, how they could behave abusively in that game of chess—they considered and sold themselves as intelligent or knowledgeable about the world—and ultimately, they were not good at all. So I decided to be selective in that case, and I share it only when I want to and on my own terms. I think the terms should be chosen by each person depending on how comfortable they feel with them, and considering that they are flexible or mutable: there will be times when they say, «*well, I don't care about this*», or whether they want to get paid or not, or to put everything in writing, or not show their face... In short, whatever each person wants and what they truly feel comfortable with, especially taking into account that, once you step out of your house, that is going to be a label they attach to you, bringing along all the prejudices

that surround it. So it will be you who has to face them.

(D). I deeply resonate with the idea that visibility must be chosen and that there must be minimum standards, and I believe it is fundamental that we learn to detect when we are susceptible to being objectified just to be turned into a news story. I am increasingly reluctant to give testimonies or interviews that are limited solely to recounting my life with HIV, or where they just want me to say what they already want to hear—unless, of course, it reaches an audience it hasn't reached before. I think, in the end, our experience becomes standardized. Well, to wrap up, what do you think we can do to ensure that people with HIV who are not visible, or who do not wish to be, can be involved in actions, policies, or decisions that directly impact our community, without feeling pressured to become visible?

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(S). [*Smiles broadly*] The first thing would be to invite them, right? For events, there should be invitations or registration forms that include an option—like a checkbox or something similar—to indicate whether someone wants to be visible or not. This is especially important for the organizers of those spaces, in case there's a press release or photographs being taken, to avoid exposing them. But they definitely have to participate; they have to be there. And then, regarding all the advancements in medical issues or matters related to people's quality of life—that *«fourth go»* of UNAIDS—they must involve as many people as possible. That is, it shouldn't just be those of us who have a voice and have used it at some point; those who are not visible must also be present, because their lives are equally important. Just because I speak publicly about this doesn't mean my life is more important than anyone else's. To give a concrete example [*sharpens her gaze*], let's say a film director asks for participation and wants to involve visible people to be the ones speaking, or even appearing in a panel discussion. Well, perhaps during

the structural planning or the writing process, people with HIV who are not visible could be involved. That way, their decision would be respected, and they would still be included. In any collective community initiative, when thinking about organization and structure, we need to create two distinct avenues: one for people who do not want to be visible, and one for those who do. But above all, we must ensure they participate because their perspective on life is wonderful and needs to be reflected. It shouldn't just be the same four of us—even if we have brilliant, wonderful ideas—because having the opportunity to learn from diverse experiences and realities will nourish us so much more.

(D). This reminds me of a short film by Lucía Egaña Roja, which reflects Lina Meruane's concept of the «*syndrome of female disappearance*», and speaks exactly to how women's experiences have been invisibilized in the AIDS epidemic. The director attempts to tackle this issue by having women's testimonies spoken through the voices of men, yielding their image in a somewhat theatrical manner. In this way, the women who cannot be visible ultimately find a medium for their message to arrive and be embodied.

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(S). Totally. Even in advertising, this has already been done using actors and actresses. I mean, there are very creative ways to approach these experiences and make people feel involved, because they are also part of the collective and our essence. Something I always say—you've probably heard it before—is that I am riding a bus and, above all, it is full of the women from my history. Some have gotten off, others have gotten on, but somehow, without the support and backing of all of them, I wouldn't have this voice of my own, or this discourse. So I always, always try to keep them present in everything I do. I believe that people who cannot show their face could perhaps lend

their voice, or a detail, or a gesture they feel represents them.

(D). This bus analogy reminds me of when my husband used to talk about our friend Roberta Marrero³, who used to say that even if we are just «*four crazy queens*»: «*we can all fit in a taxi*». I mean, if we agree, we can get involved and all ride in the same car or on the same train to go faster and be more comfortable. We just have to imagine it, too. Well, beyond everything we've talked about, I don't know if there's anything you'd like to add.

(S). I would like to add that in education, in any field—whether digital or physical—it is important to include HIV [*she adds with great certainty*]. Not for it to be the star guest, but so that it stops being one; so we stop hiding information about it. It needs to go from being the «*star*» to being standard, in a good sense of the word. Because if I talk about the flu, nobody gets too scared or thinks we need to cut funding for treating that virus. So let's think about the surroundings, about what surrounds HIV, and wherever we see something failing—or wherever it has a «*bad star*» or a bad reputation—let's try to turn it around and make it standard. So that HIV doesn't stand out, but neither does the lack of rights.

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(D). How would you like someone to feel when they finish reading this text?

(S). [*Responds in a tender and confident tone*] Above all, I want them to feel accompanied, supported, embraced. I want them to feel that there are spaces to connect and share. I myself am open to answering questions or whatever they might need. I want them to know that there are people behind the scenes doing things, and that they can turn to specific spaces so we can continue progressing together. Yes, that... I want them to feel accompanied,

above all.

(1) Parchís is a widely popular board game in Spain and Latin America, very similar to Ludo, Parcheesi, or Sorry! in the English-speaking world. It is a quintessential family game associated with childhood, bright primary colors, and simple, adaptable rules. In this context, Sara uses it as a metaphor for a safe, familiar, and accommodating environment, in stark contrast to the rigid, black-and-white, and highly strategic nature of chess.

(2) CESIDA (Coordinadora Estatal de VIH y sida) is the National HIV and AIDS Coordinator in Spain. It operates as the largest umbrella organization for NGOs working in the HIV/AIDS sector across the country.

(3) Roberta Marrero (1972–2024) was a highly influential Spanish transgender artist, writer, musician, and activist. A monumental figure in Spain's LGBTQ+ community, her work brilliantly intertwined pop culture, queer history, and anti-fascism to reclaim the narratives of marginalized bodies. Known for her unapologetic advocacy and sharp, reclamatory humor, her quote about “fitting in a taxi” reflects her deep belief in the tight-knit solidarity, mutual care, and grassroots resilience of those pushed to the margins.

*Accompanying Silence:
Reflections on HIV, Care, and Trust.*

By Emmal Brunel

I begin writing this text on the exact day that marks six months since I learned of my HIV diagnosis. I wish I didn't have to think so much about time, or divide my life into a before and an after HIV. Why should it have to be so important in our lives? And yet, it is.

When I learned my status—after getting tested at a clinic and receiving an email a few hours later—my first thought was to go in first thing the next morning to register for medical treatment. I was told that this isn't very common, as some people take days, weeks, or even months to process the news. I also heard more dramatic stories—for instance, of people who contemplated taking their own lives. What story are we told about HIV that makes us believe a life with the virus isn't worth living? It is just a virus. Although, sometimes, it feels like the virus. Especially for gay men. The story we are told is one of a life sentence, a punishment, even a destiny.

I decided to disclose my status to my loved ones because I wanted to live with it naturally. Little by little, I started telling them. But each conversation was exhausting for me; in a way, it meant reliving a kind of trauma. Being reminded of how heavy the news is the first time you receive it, just by seeing the shock on their faces.

**Emmal Brunel* is an HIV-positive marica activist based in CDMX; their work articulates thought and action against the rise of right-wing movements and punitivism.

Also, in some cases, I had to take on the educational labor: teaching about transmission, answering questions I didn't always want to answer, and receiving—however well-intentioned—prejudices and stereotypes.

There were days when I felt good, maybe happy, maybe I'd just had a good day. Then I would share the news with someone and feel like I had to cheer them up, make them feel less sad, less worried about me. I had to put my happiness aside to adjust to the impact I had caused the other person.

I know it isn't easy news. This text is not a reproach, because I don't seek to deny anyone's sadness. I am trying to offer an explanation, since several people asked me, «*Why didn't you tell me sooner?*»

36 I started disclosing it at one month, two months, three months... Some would have wanted to know on day one. An answer I can give now is: «*I didn't tell you sooner because it was exhausting to say it*».

And yet, I was able to say it. I also shared it on my social media, and it was a huge relief. I needed to feel like it was a normal topic in my life. To move on to something else, to stop living this as a mourning process. Especially, to not feel like it was a secret or a source of shame. And it is difficult because, at times, it does bring shame. That is something we must unlearn.

But I tried to make sure the virus wasn't a tragedy, but rather just another inhabitant of my body. That has been quite liberating.

However, there is a question that frequently accompanies me: why does it take each person the time it takes to talk about HIV in their life? For some people,

in fact, that conversation never arrives because they never find the opportunity to do so. Others do it only with other people who have HIV, because there they can speak without shame or fear. And there will be those for whom speaking about HIV at some point in their lives, with whoever it may be, meant losing a relationship, ceasing to be desirable to someone, experiencing rejection from loved ones, or exposing themselves to violence.

Disclosing your status is not an obligation. No one should pressure you to do it.

Recently, I was leafing through *Cuaderno de tareas* [*Homework Notebook*], edited by Andrea Ancira and Nina Hoechtl, where I found the following questions that, in a sense, seemed fundamental for thinking about this text:

Who decides how time is organized? What contradictions arise when the time of care comes into friction with the rhythms of capital? What other ways of inhabiting time emerge from care, listening, and mutual sustenance, when time is at the service of life rather than capitalist productivity?

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Knowing that I live with HIV has required time of care: waiting hours at the clinic I visit periodically (more frequently during the first few months), setting an alarm that reminds me every day to take my pill, thinking more about my diet, engaging in physical activity, preventing illnesses, and reading and researching the virus.

But also, talking to other people about my diagnosis, as I mentioned earlier, has required time and energy. As has reaching out to others who have lived with the virus longer, who are activists, who possess more knowledge

and share it, who do educational work to eliminate stigma and misinformation.

Behind the question of «*who gets to speak about their diagnosis*» lies a radical questioning of the administration of time under capitalism. Politicizing oneself, accompanying others, taking care of oneself, dismantling prejudices—all of this implies opening spaces for something the system has historically invisibilized: care work. This is compounded by illness (in a very broad sense) being read as a failure within a system where the healthy body is the hegemony.

This requires thinking not only about the care a person undertakes because of what the virus does to their body, but also about the entire spectrum of social, cultural, political, and economic possibilities that having HIV provokes.

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Undoubtedly, we cannot reflect on all of this without radically defending people's right not to disclose their serostatus as a form of self-protection. But, from within that privacy, we must find creative political strategies that include them. That is, opening conversations that do not solely feature the experience of those of us who want to or can name ourselves publicly, but giving space to those who do not. Without that possibility, the social movement would just become one more amplifier of inequalities.

For this reason, in the short time I have been attending spaces where people living with HIV gather, I celebrate that trust is placed at the center of their values. If we ever lose that capacity to respect each person's testimonies and intimacy, we will be betraying an essential aspect of the history of this struggle. For me, from my role creating content on social media, it has been

incredibly powerful to receive messages from people who do not speak publicly about their diagnosis, yet find a bit of trust in me (even without knowing me).

It is something I hope to always honor.

Rumor

By Jorge Bordello

Why are the living so bent on silencing the dead, so much so that the rumor of a knock inside a tomb terrifies an entire city?

What other force, if not fear, drives us to build marble mausoleums that a thousand living souls could not lift. Beneath such tonnage, bodies can do nothing but halt their resistance and succumb to bacterial betrayal in silence. Buried in a plot of earth, but also in time. Anything can be engraved on a fresh tombstone, and time will turn it into dogma. One can walk past a row of graves reading «*Here lies the body of...*» or «*Consecrated to the memory of...*» and yet, half of them might be empty.

The sentence to remain silent is the curator's praise. Fortunate artists—usually dead ones—move into the subterranean vault of the museum's collection; but unlike the mausoleum, which, no matter how heavy, is never airtight, the museum is time-proof, or at least as much as the asepsis of conservation allows. Devoid of acid, oil, dead skin, moisture, or contact; the artist has finally become immortal as an alienated commodity.

**Jorge Bordello* is a visual artist interested in the tensions between document, fiction, and public narrative; his research intersects with HIV.

The artist-as-acquisition plays the leading role in the collegial decision-making process. Like the severed whale's head on the deck of the whaleship, they will be asked questions—Speak, noble and venerable head!—but that head, upon which the sun now shines; which has moved amid the foundations of the world; which has seen enough to wear down the planets, will not utter a single syllable. Allowing the captain to continue his crazed monologue. Or, in the case of the curator, their research topic.

44 The point of my text is not the lack of agency among positive artists; quite the opposite, it is to point us toward a politics of silence that works in our favor within a terrain of ethnographic extractivism and labor precarity. It is an invitation to gossip. One of my seropositive friends says that the world is not used to us positive people speaking... and they cannot even imagine that we speak among ourselves, I would add.

What the art system—dependent as it is on patrimonial alienation—fails to realize is that we positive artists do not organize as a guild, but as a community. That our association is often erotic and complicit rather than professional and public; we house our memory in a rather private site that can make peace with the ephemeral malice of the encounter, the memory of the dead, and the details behind the loss. Waves of academic interest will periodically thrust publicly palatable positive artists into the spotlight. In the evening, HIVisibles and inHIVisibles gather around the edges of the institution, burning it alive with rumors, conversing history outside of historiography.

Gossip cannot be acquired; it is qualitative analysis. Precious information of subjectivity is accessed through the exchange of other valuable information, combined

with a demonstration of discernment from the interlocutor. Gossip is not a secret; it is a micro-historical process. It must be transmitted in intimacy to stay alive through proxies—its environment and social agent, respectively. Gossip must be protected during specific periods. If completely illegitimate information reaches the wrong ears—not those of the enemy, but those of the rigor of verification—the very purpose of its stealth ends up turning into mere information. These are intimacies between the mausoleum and the museum.

Why are the living so bent on silencing the rumor of the dead? Or, in our case, living gossip? Because what we say is not understood. To hear us and look at us at the same time is impossible. Terror creates a desert there.

*Who would dare to listen? Even if they listened, they would not understand. We speak an unknown tongue. If you know it, you are one of us.**

**The Toilers of the Sea. Victor Hugo.*

The Direction of the Spotlight

By MC

According to the U.S. Attorney for the Southern District of New York, «*for years, Gilead sought to illegally boost sales of its HIV drugs through speaker programs it used to pay kickbacks to doctors*»¹. It treated them to trips, meals at luxury restaurants, and paid them outrageous honoraria to participate in conferences organized by the company itself. Gilead framed this scheme as educational activities, but the attorney explains that, in reality, it functioned as a vehicle to pay covert kickbacks, with the ultimate goal of wining and dining doctors so they would prescribe their drugs.

Gilead, the pharmaceutical company that markets the drugs that keep us alive, operated corruptly for at least the years the investigation spanned, from 2011 to 2017. This implies that a good portion of its business took place out of the spotlight, amidst whispers and in the dark, in restricted-access spaces and through subtle strategies. The attorney details their practices.

Gilead is no exception. In reality, it operated like almost any other pharmaceutical company².

As this case reveals, the response to HIV is a

**Miguel Caballero* holds a PhD in Cultural Studies and is a professor at Northwestern University; his current research explores the relationship between dissident communities, antiretrovirals, and other drugs.

political and corporate infrastructure full of shadows and silences. It is built every day behind closed doors. It looks for legal loopholes and perverts language. When the patient enters the consultation room, they close the door behind them and expose themselves to the doctor's care. Often, there is violence there. When the pharmaceutical rep enters the consultation room, they close the door behind them and expose their care products to the doctor. There, it has been proven, lies corruption.

50 The corruption of corporations, healthcare institutions, and certain medical professionals is not the only battlefield for people with HIV, not by a long shot. Stigma remains rampant, as do loneliness, fear, and the challenges of aging with the virus, which we are only just beginning to understand. But when I think of visibility, I think of corruption; because it is a distortion that occurs in the shadows and which determines, to a large extent, the price of medications, the lack of options, and the lack of access to treatment and other forms of care.

This whole plot, moreover, deteriorates the trust that people with HIV place in the system upon which their lives depend.

[The system I refer to here is not an abstract entity upon which to lay the blame. It's the system's fault. No. And yes. The system I am pointing to is specific: I refer to the institutional apparatus—state and supranational, corporate, legal, scientific—responsible for the HIV response. I refer to its logic and its practices, which often occur in the dark, but which are anything but abstract. They are highly specific. One of these practices is precisely the cycle of astronomically remunerated conferences that Gilead sponsored so doctors would

prescribe its drugs and not those of its competitors.]

I was diagnosed HIV positive in 2015. It was at a well-known hospital in New York. The doctor asked me to sit on the examination table to check my lymph nodes, possible skin lesions, and my breathing pattern. Next, he took a marker out of his pocket and wrote three giant letters—A, B, C—on the disposable paper that covers the table, right next to where I was sitting.

Is there any history of heart problems in your family? he asked me.

Yes, I replied.

Then your treatment is B.

He asked me to stand up, removed the protective paper where he had written the letters, crumpled it into a ball, and threw it in the trash. He handed me the prescription and asked me to return in a month and a half. I never knew which treatments corresponded to each of the other letters. B, I found out later, referred to Stribild, Gilead's flagship drug at the time. I was overwhelmed by my diagnosis and didn't know what to ask. I practically had no voice; my head was somewhere else. Nowhere, rather. I would have said yes to whatever the doctor recommended. 51

When we pose visibility as a problem or a challenge, we are thinking about our visibility and assuming it, perhaps, as a necessary position for the struggle. Without a doubt, it is a useful tool. It is also a life-transforming experience. There is something that changes when one speaks openly about their diagnosis.

But questions arise for me. Here is one among

many:

Can our visibility also be a way of shedding light on a system full of shadows, one that, while caring for us, exploits or abandons us?

[Clarification: I consider this question within the contexts I know best, which are the Spanish and American ones. I understand it operates differently in other places.]

52 To answer, let's travel back to the origins, to the *Silence = Death* proclamation, which is practically foundational to AIDS art and activism. We continue to champion it so much that its message seems self-evident to us. Not speaking out leads to death. That's it, isn't it? Not letting oneself be noticed, not appearing in the public space opens one wound (that of the system's lack of response) on top of another wound (that of HIV infection); one debilitation (that of abandonment by the system) on top of another debilitation (that of the sorrow that usually accompanies a diagnosis).

However, this logical equivalence between silence and death does not vindicate visibility, but rather noise. It understands the field of intervention not from the perspective of making oneself seen, but from making oneself heard. Being a visible HIV-positive person in the 80s and 90s was not essential to be part of the struggle. What was required was the capacity to cause an uproar, to protest against the calculated neglect of the system. Shouts against abandonment and abuse to force a response. Commotion in the doctor's office, on the street, at the headquarters of pharmaceutical companies and national health institutions. Noise that would reveal the lies and silences upon which the world was sustained.

«Gilead entered into a settlement to avoid the costs and distractions of potential litigation», the company itself stated³. They paid 202 million dollars to stop the trial from moving forward. A settlement. Not much, in any case, for a company that, in 2024 alone, earned \$28,800,000,000⁴. It is so much money that it is difficult to read: twenty-eight billion eight hundred million dollars, or, in Spanish, veintiocho mil ochocientos millones de dólares.

What is also important here is the language, because they corrupt that as well. In that very message, they call the work of the Attorney General—who verifies companies' adherence to rules of conduct and commercial integrity—a «*distraction*». How ironic that the pharmaceutical company that demands our compliance with our treatments is sued for *non-compliance* with its industry's ethical standards. Gilead is poorly adherent. Bad, bad.

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The next time the doctor tells me I need to adhere better, I'm going to ask him not to distract me.

In *Silence=Death*, as it is read today, there is another displacement. It involves an inversion of positions in the order of the actors of communication. At some point, we understood that it was, above all, a self-directed proclamation, from us to us. The recipient of the message mutated, narrowed: the demand is no longer directed so much at the government, the industry, or science. At least not in the geographies I inhabit, which are sometimes complacent because they know they have resources at hand.

Here is my proposal: Visibility is useful when one appears for an instant in the beam of light cast by the spotlight, but we must not make our home there. We must not fall in love with the spotlight, nor let ourselves be

dazzled by it. As soon as it illuminates us, we must move, get behind it, grab it, and point it upwards—let it shine on and demand explanations and answers from this system of shadows that claims to care for us.

I write this and think back to my own diagnosis. The next time I went to that doctor, after the appointment where he prescribed what he called medication B, he told me it would be our last. He had too many patients and could no longer see me. He diagnosed me, put me on chronic treatment, and dismissed me at the next appointment. He had time to prescribe to me, but not to follow up.

54 Years later, I check his web page again. It seems that now the hospital or the law obliges them to include a section where doctors disclose—more or less, as they give few details—their «*Industry Relationships*». There, on his profile, is Gilead, with whom this doctor collaborates in «*consulting and other professional services*». The section closes with this message from the hospital: «*Patients may wish to ask their physician about the activities they perform for these companies*».

I wish to ask him those questions very much. *I wish*. If I put up visibility, let him put up transparency. The spotlight for both of us.

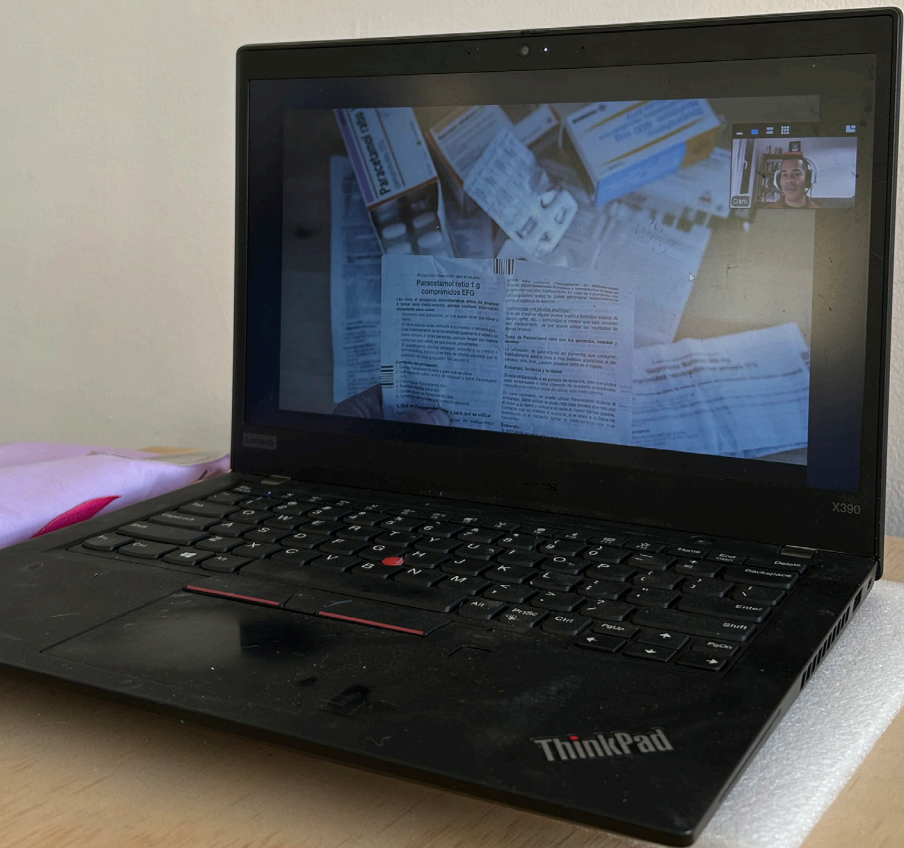
(1) “For years, Gilead unlawfully sought to increase sales of its HIV drugs, by using its speaker programs to funnel kickbacks to doctors” (<https://www.justice.gov/usao-sdny/pr/us-attorney-announces-202-million-settlement-gilead-sciences-using-speaker-programs>).

(2) The literature on the modus operandi of pharmaceutical companies is very rich. I highlight *The Truth About the Drug Companies: How They Deceive Us and What to Do About It* (2005) by Marcia Angell, which laid the groundwork for many of the critiques that followed. Angell is a medical doctor and was the editor of the prestigious *The New England Journal of Medicine* during the 1980s and 1990s, throughout the hardest years of the AIDS epidemic.

(3) <https://www.gilead.com/company/company-statements/2025/gilead-statement-on-settlement-agreement-with-us-department-of-justice-resolving-legacy-compliance-matter>

(4) https://www.gilead.com/news/news-details/2025/gilead-sciences-announces-fourth-quarter-and-full-year-2024-financial-results?utm_source=chatgpt.com

PART 2



Before We Begin.

What can writing do when narratives about the seropositive experience already seem exhausted? In a context saturated with images, medical discourses, institutional campaigns, and standardized narratives about HIV, there is a risk that the abundance of representations might, paradoxically, produce a new form of invisibility. When a story is repeated within the same frameworks, it ends up obscuring the complexity of the lives it attempts to name.

The workshop «*Sembrar la cura*» (*Sowing the Cure*), facilitated by Daniel Cortez Abreu, stemmed from this concern: to open a space where imagination, writing, and experience could converge to produce other possible metaphors. Rather than explaining HIV or describing it through dominant languages—clinical, preventive, or biographical—the proposal was to shift the point of view:

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«What happens when we stop speaking solely in terms of illness, treatment, or diagnosis, and begin to imagine the cure as a collective, symbolic, and creative process?»

Writing was the tool chosen for this shift. Writing allows us to enter another temporality: one that is slower, more reflective, and open to drifting. It also allows us to speak from different places, even from anonymity, and to build a common space using simple tools—a pencil, a piece of paper, a conversation—which remain profoundly democratic technologies. But, above all, writing can be a way to forge bonds, share experiences, and imagine other possible futures together. Starting from an initial prompt—«*At the bottom of the medicine bottle, a seed appeared...*»—the participants began to think of the cure as a process of sowing.

What would that seed look like? What kind of soil would it need to grow? What kind of plant would HIV be if we imagined it as a living organism within a broader ecosystem? The answers to these questions did not seek medical solutions, but rather aimed to open fertile ground for metaphor, memory, and invention.

From that exercise emerged the texts that make up the following section. Some verge on poetry, others on narrative, memory, or dream.

The project also proposed imagining a package insert for a possible future: a kind of collective letter to accompany the different imagined cures. Not as a traditional pharmaceutical instruction manual, but as a gesture of anticipation. A way of looking forward and asking ourselves what forms of life, care, and justice could grow from these seeds.

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The second workshop of this project was facilitated by the artist Jorge Bordello. In this space, visual creation was explored through resources that inhabit the everyday lives of the participants. Based on a methodology focused on the tensions between document and fiction, the private archive and the collective narrative, seropositive trajectories were channeled toward graphic production. In this way, the image was not conceived as an illustration subordinated to the word, but was instead endowed with an autonomous nature. Through the intervention of these resources, the diagnosis, the body, and intimacy were articulated as a political montage confronting public life.

1 Jul 2025

Friend, a year ago this month I was diagnosed with HIV, and I am honestly so grateful to be here and I'm so grateful to have you in my life and that you were truly my biggest support, a lifetime won't be enough to thank you for how good a person you are to me, a thousand thanks for being my best friend, may God and life always surround you with all the good you deserve, thank you so much Tere 🥺❤️

11:01 p.m. ✓✓

2 Jul 2025

Aw my friend, you don't have to thank me for anything, you know that meeting you brought so much good to my life and knowing you weren't doing well devastated me, I've told you and you've told me, we will always be there.

If you are still here today it's because you gave yourself a second chance, I only supported what you decided and obviously that's all I wanted.



Dear friend, it is the year 2745 and this virus still lurks, playing its games on the trampolines of my veins. I have seen—and I do not know how many more I shall see—the deaths left behind by the circumstances of our journeys, and the death by monotony that accompanies the sheer passage of life. I have kept abreast of the advances in medicine. And yet, I find myself facing the same questions. I am working with Dr. Fausto Weber, a genius in molecular biochemistry applied to the behavioral development of microorganisms. Although his research seems promising, we still lack the clinical trials, the test subjects, and the approvals from health and medical institutions.

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Since I joined his laboratory, located beneath the eternal ice of Antarctica, where the silence is broken only by the pulsing of fusion reactors, I have felt time grow denser. Here, beneath kilometers of glacial ice, the white walls of the complex emit a light that emulates a perpetual dawn. There are no nights. There are no seasons. Only the continuous hum of the machines measuring the virus's respiration in real time. The virus, which we have begun to call Morfea-L, does not behave like a traditional disease: it does not attack the lungs, nor the immune system, nor even directly the DNA. What it does is anchor itself to the autonomic nervous system, infiltrating like an alien thought, an echo that repeats itself in moments of stillness. Many who seemed healthy died in their sleep, without pain, without spasms. They simply stopped dreaming, and then, they stopped waking up.

Dr. Weber does not speak much. He has glassy, gray eyes, as if he had seen a thousand visions of the future and none were worth telling. But when he does speak, his words carry more weight than the protocols of the Solar Medical Academy. He told me once: *«It is not about defeating the virus, but deceiving it. We must make it believe it has already won, so that it lowers its guard when the counterattack arrives»*. Since then, we have designed the substance known as Nemesis V. A synthetic, almost ethereal compound that mimics the brain's electrical signals in the REM state, but with a lethal chemical twist.

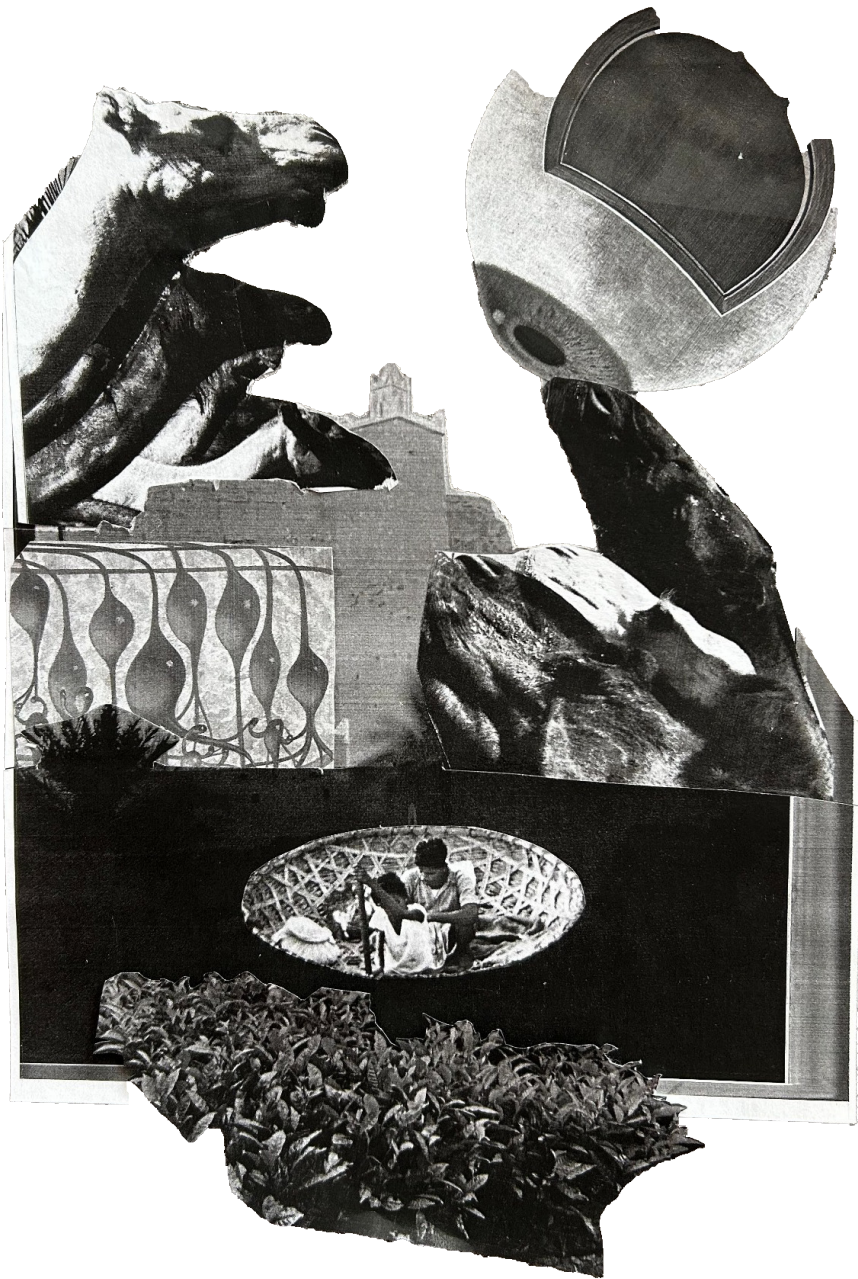
64 I have mentioned to him that its administration must be aggressive for its effectiveness to be one hundred percent guaranteed. My hypothesis regarding the procedure is to place the patient face down, with minimal anesthesia; they must feel every movement of the scalpel; the incision must be made between C3 and C5. Dr. Fisher, who died during a solar radiation storm last year—a twist of fate from which I have yet to recover—was the first to observe, under a quantum entanglement microscope, a new nerve, almost imperceptible due to the shape of the spinal cord in that area. He called it the igneous fiber. It is so thin that it does not conduct conventional motor or sensory impulses. Rather, it acts as an encrypted line of communication between the spinal cord and a remote gland, located in the brain's third ventricle, whose function was previously unknown.

Thus, the administration of the substance must be swift; at every moment, the patient must be asked if they still have control of their extremities. A loss of sensation in the hands or feet means the igneous fiber has already been touched—and then, there is no turning back. If the process is a success, the substance will stimulate this tiny nerve, which in turn will send the correct signals, and the brain will produce a new hormone, hypnolin, capable

of confusing and slowly killing the virus. Not through destruction, but through emotional asphyxiation: the virus relies on sadness, on boredom, on suspended time. Hypnolin simulates a surge of vivid memories, of impossible joys, as if the brain were reliving every moment of ecstasy in a chain reaction. The virus, failing to recognize the emotional environment, retreats. Slowly, it disintegrates, like a shadow beneath the midday sun.

One would only need to be medicated for two months. It would be more comfortable. Though one cannot be sure. The first volunteer, a 68-year-old man who had been a philosophy professor on Mars, received the treatment three weeks ago. During the first few days, he screamed. Not from pain, but from memories: his first bike, his mother's face when letting him go at school, a stolen kiss in a zero-gravity tunnel. Then he fell silent. Now he smiles, constantly, even though there is no one with him. Last night he told me: "I hear the words I never said out loud." The virus, according to the scanners, has reduced its load by 98%. Something is working. Or perhaps, something new has begun. 65

What year is it, as you read this letter?
Or rather:
Have you stopped feeling alive?
Are you cured?



Package Insert.

1.

For decades, HIV has been like an arid terrain where it seemed impossible for anything new to sprout; but in the midst of that soil, a small plant has begun to sprout, fragile yet full of life. Its presence heralds the promise of change, which is the cure. Thus, the plant forms leaf by leaf, transforming itself into a possibility. **67**

Every sprout of this plant represents patience, motivation, and trust.

2.
Before taking.

Keep this leaflet, as you may need to read and enjoy it again.

68

This treatment has been prescribed for you.

If you experience any of the following reactions, do not continue the treatment and consult a professional you completely trust:

Catastrophe: The crisis of faith, the loss of the meaning of life.

Emptiness: The hole in the soul that nothing can fill.

Anxiety: The desperate attempt to control the panic that surrounds you.

3.

How to use this medicine?

The usual dose for each person (whatever your doctor has told you).

Take the medicine at night in good company, with sweet bread, chocolate, or coffee. 69

Take the medicine and the correct doses.

What should I do if I forget a dose?

Do not get upset. Take it the following morning with your breakfast.

Remain calm, the cure is within you.

Have you slept well lately?

4. **Side effects.**

Patients may experience euphoria for several days.

70 ***Momentaneous lucidity-blindness:*** It is possible that after the euphoria, at its highest point, the person may feel blinded. The pupils will register a powerful light for a couple of hours, accompanied by a touch of melancholy.

Selective memory loss: As the moment of blindness subsides, the person will begin to lose the memories that accompanied their diagnosis. They will remember people, certain dates, but will gradually forget everything related to HIV. It is recommended that, while this happens, the person write a diary to preserve them.

5.
Storage and Preservation.

Conservation Ritual: Consider three stones brought from the volcanoes Popocatépetl, Iztaccíhuatl, and Matlalcueyetl. These stones must be exposed during a full moon night, beneath the evening dew, and then submerged in breast milk for seven days, mixed with boiling white chocolate powder.

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Finally, three drops of lemon are added to turn the preparation into requesón.

Among the adverse conditions are love, the contemplation of the one who consumes it; madness, and above all, the congruence between doing, saying, and thinking.

Constant drowsiness in the face of educational and social disparities. Indifference to the affection of a few or many unconcerned relatives.



Ecos: ¿A quiénes no estás escuchando?

Echoes: Who aren't you listening to?

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Who owns the narrative about HIV? Historically, our stories have been extracted, translated, and cataloged beneath the clinical, sterile gaze of the Global North. The book *Ecos: Who aren't you listening to?* is a response to that tradition.

Born among the members of *cepa*, a community of HIV-positive people in Tlaxcala, Mexico, this book collapses the hierarchy between researcher and researched. Through raw dialogues, analog collages, intimate photographs, and everyday digital archives, we seize the word and the image to reclaim our right to epistemic justice.

Coexisting within these bilingual pages are the voices of those who live publicly with their diagnosis, alongside those who have turned anonymity and opacity into a creative trench. We do not seek comfort, nor do we attempt to fit into fixed concepts. What you hold in your hands is a collective montage, a way of inhabiting uncertainty, and a radical demand: the right to tell our story with our own accents.

