ABIA Bulletin

Brazilian Interdisciplinary AIDS Association | December 2018 | nº 62

ABIA, 30 YEARS

A History of Solidarity and Struggle for Social Justice
EDITORIAL

Why does the word “solidarity” appear in all the articles and the interview in this special edition celebrating the 30th anniversary of the Brazilian Interdisciplinary AIDS Association? Solidarity is intrinsic to the history of ABIA and to the history of AIDS in Brazil, and the word thus has a history in ABIA.

Founded in 1987 by sociologist Herbert de Souza, or “Betinho”, physician Walter Almeida, and other important leaders, ABIA was born of the search for effective answers to the AIDS epidemic. Betinho was probably the first person in the world to associate human rights with AIDS. He was also the first person to define solidarity as a political concept involving empathy, participation, mobilization, leadership, respect, and equal rights.

ABIA was also the first institution in Brazil dedicated to the fight against AIDS that was founded by a person living with HIV. This established a political and institutional field in the organization’s history. Solidarity is thus both a principle and an integral part of ABIA’s daily reality and the guiding principle for dozens of actions, projects, seminars, and publications in the institution’s history.

This spirit of solidarity motivated the institution to use culture as a tool to rethink norms and overcome the prejudice and stigma still attached to AIDS. Filmmaker and researcher Vagner de Almeida and journalists Jean Pierry Leonardo and Jessica Marinho address this spirit in the article “Cultural activism: the art of transforming the world”. Cultural productions by ABIA have always been important allies in paving the way for activism.

The democratization of information has also inspired action by ABIA in these last 30 years, as discussed by journalist Angelica Basthi in her article “A historical contribution to the democratization of information”. For example, advocacy and lobbying by ABIA (together with partner organizations and movements) were essential for passing Brazil’s Freedom of Information Law. Fernando Seffner, Professor of Education at the Federal University in Rio Grande do Sul (UFRGS) and longtime ABIA board member, has written an instigating paper on ABIA’s 30-year history with the title “Humility, illness, sexuality, vulnerability, solidarity. Age. ABIA, 30 years”.

ABIA president Richard Parker brings alive the memories featured in this edition through an exclusive interview entitled “ABIA, 30 Years: a history of solidarity and struggle for social justice”. Next, Veriano Terto Jr., vice-president of the institution, in his article “ABIA and life with HIV and AIDS in Brazil” translates the full meaning of living with HIV and AIDS through the brilliant contributions by people who lived with the virus, like Herbert Daniel, and who were fundamental in the history of ABIA.

The tireless struggle for access to medicines that mobilized Brazil and the world is told by journalist Felipe de Carvalho and Pedro Villardi, a PhD student in Collective Health at the Institute of Social Medicine (IMS), in the article “Our struggle is for respect, for the right to medicines”. Finally, psychologist Salvador Corrêa and physician Juan Carlos Raxach summarize the definition of the deepest feeling of solidarity that has motivated ABIA throughout these 30 years in the article “The path to solidarity is knowing how to listen”.

ABIA is celebrating 30 years with the certainty that it will remain steadfast in the search for effective answers to the HIV/AIDS epidemic in Brazil and the world.

Enjoy this special anniversary edition!
Ever since ABIA was founded in the 1980s by sociologist Herbert de Souza (Betinho), physician and activist Walter Almeida, and other leaders, the institution’s commitment has been to the fight against the AIDS epidemic based on social justice, human rights, and the end of stigma and discrimination against people with HIV. A key strategy that ABIA has used in this struggle has been cultural activism, based on the use of symbolic language to shock, shake, challenge norms, and transgress. The cultural activism practiced and promoted by ABIA has always been associated with high-quality information, emotion through art, and political mobilization.

Throughout its history, ABIA has acted under the premise established by Betinho that an organization to fight AIDS should mobilize social movements. It was a time in Brazil’s history that marked the beginning of the organization of these movements on various fronts and in various dimensions of the HIV/AIDS epidemic.

Betinho believed that the epidemic was not just about public health, but about a fundamentally political and cultural problem that called for a collective answer. Cultural activism was thus a way to respond to the difficulties and challenges raised by various types of violations in the face of demands. One of the most successful institutional strategies in ABIA’s 30-year history was to use culture as a political resource in the struggle against sexual violence, structural violence, discrimination, prejudice, and stigma.

Among the various areas of multi-sector and interdisciplinary cultural activism, in the late 1980s ABIA was already actively developing sociocultural and political interventions with the arrival of the writer and gay activist Herbert Daniel. Daniel joined ABIA as a member of the project called “The Social Impact of AIDS.”

Vagner de Almeida, Jean Pierry Leonardo and Jessica Marinho

1 Vagner de Almeida is a filmmaker, researcher, and coordinator of the project Sexual Diversity, Health, and Rights among Youth; Jean Pierry Leonardo and Jessica Marinho are journalists and project assistants.

2 Read more about cultural activism on the website of the project Sexual Diversity, Health, and Rights among Youth, at www.hshjovem.abiaids.org.br
Various projects marked this 30-year historical timeline. Numerous campaigns were organized due to the need to work with specific populations that were turning to ABIA as a source of information, prevention, and education. One example was the project for construction workers, with an entertaining lead character called “Zé Cabra Macho” (≈ Iron Man Joe) starring in videos in cordel format (like chapbooks) narrated by popular TV and film actor Lima Duarte, with the language of migrant workers from Northeast Brazil living in Rio de Janeiro. Other groups that received special attention on prevention and safe sex were merchant sailors and men who have sex with men.

Other key groups at the time, like street kids, teens, and women, were contemplated with specific materials on prevention. Examples included pamphlets in comic-book format distributed to street kids and the videos Que qui é esso tal de AIDS (What’s this AIDS thing all about?) and Meninos de Rua (Street Kids), both in 1989, Amor, vida, viva! (Love, Life, Live!) in 1991, and Se você me ama (If you love me) in 1992.

To promote solidarity and the basic rights of people living with HIV, ABIA collaborated with other important institutions to draft the Declaration of the Fundamental Rights of People Living with the AIDS Virus.

In this timeline of cultural activism, in 1993 ABIA launched the “Homosexualities Project” to create an alternative approach and focus on issues related to civil rights, sexual oppression, discrimination, stigma, and safer sex. At the time, these terms were still not references in the world of HIV and AIDS. This same period witnessed the first “Expressionist Theater Workshops on Sexuality and AIDS for Men Who Have Sex with Men”, resulting in a theater play, book, and the documentary film, Cabaret Prevention, with intense participation by the volunteers participating in the project, who wrote the entire script and made all the costumes. The play set off shock waves in media channels and was one of the last productions staged at Teatro Alaska (a cradle of gay culture in Copacabana).

The “MSM Project” (Men Who Have Sex with Other Men) also included acts like “No Matter With Who”, reclaiming erotization and daringness with the photograph of a condom on an erect penis, the pamphlet “Threesome” (exploring bisexuality and sexual diversity, eroticism, and erotization, sexual phantasies together with safe sex, etc.), and somewhat later the publication “Tudo Dentro” (roughly “All In”), to value the prevention of sexually transmitted infections (STIs). In addition, posters and postcards with messages like “Silence = Death”; “Action = Life” aimed to value gay and HIV-positive global/transnational activism with strong images that broke with immobility and inaction and linked a militant, misbehaved response to the epidemic.

One of the most sweeping and revolutionary activities by ABIA was conceived in 1996 through the “Arayê Project”, focusing on the African-Brazilian community and combining education and prevention through awareness-raising, development, and solidarity...”
The project drew on African-Brazilian traditions to disseminate various forms of information and contents. The project began with the Arayê Newsletter, first distributed in Rio’s Lapa neighborhood, where the Health Tent had already started (with prevention through distribution of condoms and educational materials on HIV/AIDS in the local community). These were creative ways of using the language and symbols of African-Brazilian culture to confront the epidemic.

The need to build capacity among young people led ABIA to develop other cultural and educational activities like photography and computer classes and video workshops (held at the institution’s headquarters). The “Health Troupe” was also created, mixing elements and techniques from theater arts, circus performance, dance, and percussion with young people from different age brackets, but whose common thread was belonging to low-income communities in Rio de Janeiro. The workshops addressed such issues as racism, violence, stigma, reproductive rights, HIV and AIDS, prevention, and teenage pregnancy.

This amazing repertoire of cultural productions, films, and documentaries, which are still staged and screened and are winning awards around the globe, also included creations with participants that are still active in the workshops today, besides numerous films ABIA has produced over the years, such as: Butterflies of Life; Just One Day; Sexuality and Hate Crimes; I’m a Woman, a Brazilian, and a Lesbian; Homosexuality, Old Age, and HIV Prevention; Young Brazilians and their Challenges; and the more recent Condoms Still Have an Expiration Date. To reclaim the daringness and erotization of sexuality through the project Sexual Diversity, Health, and Rights among Youth, in 2016 ABIA launched the Prevention Calendar, with participation by volunteers representing different genders, sexual orientations, races/ethnic groups, ages, and body types. In this context, the Sexual Diversity, Health, and Rights among Youth project resumed (after 20 years) expressionist theater classes at ABIA’s headquarters. The expressionist theater workshops focus on issues related to HIV and AIDS, stigmas, and prejudices experienced by the young people themselves and adults, among other issues in society, through texts created during the classes and by sharing personal experiences.

In addition, during the 11th Congress on HIV/AIDS and 4th Congress on Viral Hepatitis, project coordinator Vagner de Almeida and other members of the ABIA team participating in the two joint congresses gave a presentation entitled “Which prejudice did you bring today?”, which is also part of the Expressionist Theater Workshop. One of the high points in the 30-minute presentation was when a young volunteer took off his clothes as a protest against all of society’s daily impositions. The congresses also featured activities by the Working Group on Intellectual Property (GTPI), coordinated by ABIA, interacting creatively with civil and political society to develop dialogues and contribute to ABIA’s success as a nongovernmental organization.
with the audience through cultural-political demonstrations, like drumming on two huge boxes of sofosbuvir and tenofovir + emtricitabine (Truvada) and the symbolic mock wedding of ANVISA (the Brazilian national drug regulatory agency) and Interfarma (the Association of the Pharmaceutical Research Industry): in the wedding ceremony, two activists staged a tongue-in-cheek theater skit in the name of big business, with the shareholders’ blessing, in the attempt to destroy the Unified National Health System “until social control do them part”.

As one of the activities celebrating ABIA’s 30 years of activism and struggle, over the course of 2017 the institution has developed the Guide to Safe Sex, which consists of reclaiming daringness, sensuality, erotization, and sexuality in the context of AIDS. The publication, scheduled for nationwide distribution, is being developed jointly by various young people and adults, who participated in drafting the text to accompany the photo session that will illustrate the publication.

Everyone that has participated in the cultural activities promoted by ABIA in the last 30 years knows that discipline and solidarity have been crucial factors for individual and collective milestones in their own lives. This is central to cultural activism, when one understands that through the collective body, every citizen is valuable to society. We reiterate that the quest to maintain dialogue with civil and political society contributes to ABIA’s success as a nongovernmental organization in the struggle for social justice and the rights of people living with HIV and AIDS in contexts that are opposed to our ideas and ideals.
AIDS emerged in the early 1980s and rapidly became one of the largest global epidemics in history. The first cases in Brazil were reported while the country was still undergoing re-democratization. It was a time of reestablishing political ties and strengthening civil society. The epidemic’s devastating effect required civil society’s mobilization to deal with it. ABIA was founded by sociologist Betinho (Herbert de Souza) in the midst of this avalanche of events. When he was diagnosed with HIV, Betinho took the initiative to found the association, with democratic access to information as one of its pillars. Even then it was crucial to guarantee the population’s access to information in order to leverage mobilization and press for answers to deal with the grave situation with the epidemic. Betinho was a visionary, stressing that the Brazilian government’s “social” agencies like the Ministries of Health and Education were attempting to maintain a more open and democratic dialogue with organized civil society. Meanwhile, the more “technical” government agencies (like the Ministries of Science and Technology, Industry and Commerce, and others) kept a greater distance from society, as they had done previously under the military dictatorship.

Although re-democratization was already underway in Brazil, the country’s Freedom of Information Law (no. 12,527) was not passed until 2011. The law’s purpose is to regulate access to public information and encourage transparent management of information in government agencies, state-owned companies, and public foundations, among others. For example, the law guarantees the right to obtain information

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contained in records and documents, regulates the use of public funds, etc. The Executive, Legislative, and Judiciary Branches, the Office of the Public Prosecutor, and other government agencies are thus required to provide access to public information and its publication.

Brazil’s Freedom of Information Law has important implications for health, since access to information can be a “life or death” matter. Access to information can also mean ensuring dignity and human rights for everyone, especially the most vulnerable. In Brazil, poor people are usually the ones most affected by social, gender, racial, and ethnic inequalities.

The law is thus interwoven with ABIA’s struggle, with democratic access to information as the main thrust of its work ever since it was founded. ABIA has helped guarantee that information on the HIV/AIDS epidemic and related issues circulates objectively, transparently, accessibly, and in language easy to understand. For example, the law has been essential for accessing trade regulations and patents, among others, as we shall see next.

ABIA’s initial objective was to guarantee that society – and especially people living with HIV and AIDS – had access to essential information for understanding the epidemic’s size and impact in Brazil. With the experience acquired over the years, access to information has also proven to be a powerful way of fighting the exclusion and marginalization plaguing the populations most vulnerable to HIV. There was also an evident need to critically monitor public policies in the response to the HIV/AIDS epidemic in Brazil.

For ABIA, the best defense in the AIDS struggle has always been information, which we view as a human right. In the health field specifically, freedom of information guarantees other rights in practice, like human rights as mentioned above, whose principles are based on respect for dignity and each and every person’s value. ABIA has thus taken groundbreaking measures to promote freedom of information, materialized through exposés, campaigns, pamphlets, documents, reports, newsletters, videos, events, and participation in Brazilian and international congresses.

For example, in the late 1980s and early 1990s, the institution denounced the lack of government programs and policies to respond to the AIDS epidemic. The strategy focused on intense participation by leaders with the greatest visibility in the mass media, like sociologist and ABIA founder Herbert de Souza and writer Herbert Daniel, among others. Many critiques were aimed at the government’s poorly conceived educational initiatives and the refusal by public officials to fund treatments for HIV and AIDS.

The institution became one of the main references for the circulation of information on prevention and education related to HIV and AIDS. “Living Life Positively” (1989) was addressed to people that had received an HIV diagnosis. The main focus of the message was to redefine “positive” and promote interpersonal solidarity.
In 1988, ABIA launched a series of educational pamphlets including “What AIDS is, how it attacks, and how to avoid it”. That same year the association launched another unprecedented pamphlet, “What’s the safe harbor against AIDS?”, this time targeted to merchant sailors.

Other communications activities that consolidated ABIA as an opinion-maker and source of high-quality information on HIV and AIDS were the videos for construction workers (like Love and Life in the Age of AIDS and If You Love Me), plus specific leaflets for men who have sex with men (MSM), like “Sex Without Risk Between Men”). Thus, the late 1980s and early 1990s witnessed campaigns based on the experiences of the group most affected at the time, MSM, and with easily accessible language. The goals were to reduce the risk of HIV infection in the most vulnerable populations and to mobilize society in general with high-quality information.

ABIA’s interdisciplinary profile allowed the institution to work in the academic field as well. Through collaboration with renowned researchers affiliated with leading academic institutions, ABIA organized cutting-edge research projects to develop scientific data and contribute to the response to the epidemic. One such project was “The Social Impact of AIDS” (1987), funded by the Ford Foundation, and in the 1990s the projects “AIDS and Women in Northeast Brazil”, funded by Oxfam, and “Women with AIDS”, funded by the International Center for Research on Women. The early 2000s (2000-2003) featured the projects “Responding to the HIV/AIDS Epidemic in Brazil: methods controlled by women for HIV and AIDS prevention for the African Brazilian community”; “Social Policy, Development Models, and International Health: analysis of the development of HIV/AIDS prevention programs and policies in Brazil”; “Combination Therapies in Developing Countries: experiences with adherence to AIDS medication in Brazil”; and “HIV/AIDS Prevention for Young Male Low-Income Sex Workers in Rio de Janeiro”, among others.

ABIA also published articles and news stories in various media outlets and dozens of revolutionary books, like the historic works by Herbert Daniel, Life Before Death, and AIDS: the third epidemic, the latter co-authored with Richard Parker. Other historic books were the Portuguese translation of AIDS in the World, by Jonathan Mann et al.; AIDS in Brazil, organized by Richard Parker, Cristina Bastos, José Stalin Pedrosa and Jane Galvão, The
Construction of Solidarity: AIDS, sexuality, and policy in Brazil, by Richard Parker and The Cure for AIDS, by Herbert de Souza. ABIA also launched the first book on AIDS and women in Brazil: Breaking the Silence: women and AIDS in Brazil, organized by Richard Parker and Jane Galvão.

These initiatives spearheaded successful strategies that linked high-quality information to broad circulation. Another strong characteristic of ABIA’s action over these 30 years has been the institution’s on-going series publications. Some were created back in 1988, like Ação Anti-AIDS and the ABIA Bulletin, which is still published today. Others emerged in response to emergency demands, like the Latin American Solidarity Newsletter (1990); Arayé Newsletter (1996-2000); the series Extra G Newsletter (2003-2005), ABIA Annals (2002-2005), ABIA Collection (2004-2011), Newsletter on Sexual Diversity, Health, and Rights among Youth (2015), and numerous booklets on prevention, sexuality, and access to medicines. To support access to all these documents (publications, studies, posters, and others) ABIA created the Documentation Center to make the collection available to the public and disseminate information and analyses on the epidemic and the dynamics stemming from it.


From the perspective of Brazil’s Freedom of Information Law, ABIA’s experience with the Working Group on Intellectual Property has shown that there is still a long way to go. From May 2012 to January 2014, the Working Group filed 44 petitions for access to information, of which 32 targeted the Ministry of Health. According to documents with the Working Group, only 5% of all the petitions resulted in full access. 19% of the cases resulted in incomplete replies. The main problem was the high denial rate: 75% of the petitions were turned down, claiming that the information was confidential. The petitions focused mainly on Productive Development Partnerships (PDPs) in the health sector. These contracts involved more than 100 Brazilian laboratories (both public and private). Without access to such information, according to the Working Group, the agreements that impact drug prices are still shielded from view and pose persistent obstacles to universal access to medicines in the country.

Thirty years have gone by and the world is now living in the digital age, with information circulating at lightning speed and going viral on social networks. Brazil’s Freedom of Information Law is in force, but the country still has a long way to go to guarantee access to information and enforce human rights for everyone, especially in health. We Brazilians are still struggling for full access to information on drug procurement, drug prices, and technology transfers between governments and pharmaceutical companies. ABIA is true to its mission to make such information available to serve solidarity, social justice, and democracy.
ABIA, 30 years

Celebrating 30 years is more than reaching the first great milestone.
It’s more than being able to look back.
Celebrating 30 is a time to be amazed.
When one needs wings to soar over the abyss.

ABIA’s 30-year history in the AIDS struggle does not fit into a timeline, nor is it a straight line, nor is there an exact beginning, middle, and end. It is much more than a collection of facts chronologically ordered in time. ABIA’s history has unfolded in many different times, many epidemics, many populations, many concepts, on many fronts, in many governments, and in many public policies, because there are many epideims, many situations of vulnerability, and many links between AIDS and such diverse issues as drug patents, safe sex, women’s status, moralities, transvestites and transsexuals, prevention and pleasure. In short, it has been 30 years, but with multiple timelines.

In 1988, ABIA participated in the December 1st demonstration alongside personalities like drag queen Lorna Washington.
ABIA marched in time, came on time, fought against time, and survived many setbacks over time.

ABIA’s history can be seen as a conceptual engine, producing concepts as tools for struggle, ideas, resources, values, units of knowledge. Militant ABIA, academic ABIA. An ABIA that knows that a concept is something you launch into the world. A concept doesn’t describe a situation, it invents a way to deal with the situation, defines relations of force, enlightens actors, lights the way, points to solutions, warns of traps. We can glean various strategies from these 30 years in the ways ABIA’s theoretical and conceptual production have dealt with the response to AIDS.

Consider ABIA’s action with the production of historical concepts in theoretical and activist thinking, in the analytical arsenal for interpreting AIDS. Or the reclaiming of concepts that had been forgotten or used in other contexts. This was done in confronting the many faces of AIDS with such categories as living with AIDS, a cure for AIDS, civil death, death foretold, solidarity. Whether invented or reclaimed from elsewhere, such concepts made sense and gained importance in the Brazilian response to AIDS. ABIA has often adopted the curious practice of drawing readers aside, as in the case of “The end of AIDS”, and introducing them into another, more enriching discussion of other meanings for AIDS, other purposes for the struggle, other ultimate possibilities. We have the categories created in the academic community, somewhat timeworn, but nevertheless displaying vigor and theoretical and political productivity in publications, acts, and struggles by ABIA. Examples of such categories are vulnerability, prevention literacy, and human rights. The strategy here was to shift the concept from academia to the health system, to the prison system, to work in poor communities, to public policies, to the global AIDS struggle. Along the way, the concept was turbocharged and proved its worth!

We dared to establish innovative links in the response to AIDS. An example was the project “Religious Responses to AIDS”, for those who thought religion always ran counter to the fight against AIDS. Another case was “Prostitution and AIDS Prevention”, taking a new slant to the notion that some people spread AIDS while others prevent it. “Old Age, Homosexuality, and AIDS Prevention”, to show that where some might imagine that sex is a thing of the past, not only is there still sex, but also prevention. The theoretical and activist engine also produced sonorous and
powerful conceptual propositions that forced people to think, as in “the ideological virus” and “the end of the end of AIDS”. ABIA sought out new partners and opened new frontiers in the struggle through projects like “Intellectual property rights, patents, and access to medicines as human rights”. Acknowledging that AIDS will be with our society for a long time, we looked to the future with themes like “reinventing prevention in the 21st century” and “living in serodiscordant relationships”.

ABIA’s 30 years have been ripe with powerful, vigorous activist theoretical production that refuses to not talk about sex. Conceptual production that addresses sex, not only sexuality, that discusses sexual rights but does not fail to talk about sex. Theoretical production that encourages people to have sex, that has sex, that does not give in to narrow-mindedness, since the discourse of prevention often gets bogged down in an aseptic approach to sexual life. With no fear of talking about sex, the materials produced by ABIA speak like this: Enjoy, Come, Have Sex. Live. Have Pleasure. Lollipop. Extra G. Talk about AIDS, talk about physical exercise and AIDS. What’s more, ABIA invented a project with the name “Cabaret Prevention”, messing with the heads of people who think those two words don’t go together. Academia has trouble getting its head around such concepts, but ABIA has succeeded in producing them by mediating concepts with activism. ABIA has shown strategically that it was necessary both to invest in proclaiming that “AIDS is everyone’s disease” and simultaneously develop policies for “more vulnerable populations”. Some might ask: is AIDS for everyone, or just for some? It’s not sim- ply for everyone, nor is it only for some. The materials, texts, campaigns, and actions by ABIA have shown conceptually that this is one of the most sophisticated exercises. Blazing a coherent trail in two different theoretical directions with policies and activism is not for everyone!

And we have authors that ABIA included decisively on the AIDS agenda, who invented new possibilities, new and powerful ways of thinking. One key example is Paulo Freire, for creating strategies in prevention, education, and respect for others. Another example is Erving Goffman, for rethinking AIDS-related stigma and discrimination. Still another is Jeffrey Weeks, for conceiving diversity as a non-hierarchical relationship between different people.

When all is said and done in these 30 years, one might still say that ABIA invented practically nothing in terms of new concepts. But it did draw on what had already been thought and said by so many people, making innovative connections and new uses in the process. Does that sound unimpressive? It’s not what Roland Barthes thinks when he says that the world has few themes, but infinite arrangements. More poetically, Manoel de Barros says, “What is done best is said in another way.” With such energy, let’s have 30 more years of such productive work at ABIA!
ABIA, 30 Years
A History of Solidarity and Struggle for Social Justice

Richard Parker, 61, is one of the oldest members of ABIA. He was elected president of the institution in 1998, occupying the place left by sociologist Herbert de Souza, “Betinho”, founder of the NGO, who died in 1997 as a result of AIDS. But Parker had joined ABIA earlier (he joined officially around 1988) and his involvement with AIDS goes way back, as one of the first AIDS researchers in the world, starting with his PhD which he began in 1981. He was an enthusiastic admirer of Betinho and a personal friend of journalist, writer, and activist Herbert Daniel, who also died from AIDS in 1992. In this interview, Parker offers an inventory of ABIA’s 30 years and explains why the institution’s history has been written so closely linked to the history of AIDS in Brazil. Parker predicts new confrontations in the coming 10 years: “We should be prepared for a long, hard battle. We need to be realists about what we’ve achieved thus far and what needs to be done on the rest of the path until we reach a future in which AIDS is controlled.” Check out the following pages!
ABIA – Tell us a little about how you came to ABIA.

RICHARD PARKER – The first time I set foot in ABIA was in 1988, maybe late 1987. But the story is a little longer, because I began working with AIDS very early on. I was doing my PhD at the University of California in Berkeley in 1981 when the global epidemic began. The first reported cases were in California. I came to Brazil for the first time in 1982 to begin research for my PhD, and that was the year the first case of AIDS was reported in the country. So, I have been following the epidemic in Brazil since the beginning, and I started some preliminary contact with ABIA at the time, before it was even founded. That was in 1983, when I read a paper by Herbert Daniel, one of the first people to write about AIDS in Brazil.

I came back to Brazil in 1985 on another research stint, and I looked up Daniel. He was living in the Santa Tereza neighborhood at the time. My partner Vagner de Almeida and I went to interview him. That was when we met him and Claudio Mesquita, his partner. We became friends right away and began to exchange ideas on the epidemic. Daniel was involved in ABIA in the very first discussions on creating the institution. He was part of the first team at ABIA. Daniel was the writer who basically wrote everything that ABIA published after it was formally founded in 1987. So, it was through Daniel that I first made contact with ABIA.

I was also doing consultancy work for the Ford Foundation, and Ford started funding ABIA in 1987. My role was to help the Ford Foundation discover how it could do something to help deal with the epidemic in Brazil. That was the basis for my relationship with ABIA: a personal friendship with Daniel, my general interest in the epidemic’s political dimensions, the work I was doing at the time with the Ford Foundation, and the fact that ABIA was one of the first institutions funded by the Ford Foundation in AIDS. This combination of things led me to begin to interact with ABIA starting in 1988.

ABIA – You mentioned that your PhD focused on AIDS...

PARKER – My PhD focus was not really on AIDS, but more on sexuality. But the focus was on sexuality, and AIDS cuts across sexuality. This link became more or less obvious right from the beginning. And that was what led me to begin the work and finish my PhD in 1988. We came back to Brazil that year to do new research, this time with politics and AIDS as central themes, I mean, to understand how policy relates to AIDS. ABIA was in a sense my natural home in Brazil, because it was the institution at the center of discussions on politics and AIDS at the time.

ABIA – What really caught your attention and what motivated you to embrace this cause?

PARKER – There were several things. I lived in epicenters both in the United States and here in Brazil in the two cities where the epidemic emerged, within the gay community, and as a gay man I identified with all these things from the beginning. Many of my friends were dying. It was a time with a huge impact. I think people who only found out about AIDS after the treatment appeared, starting in 1996, may not have this same perception. But for someone who lived the first decade of the epidemic, it was a terrible, tragic situation. People were dying right and left, and it was all with a lot of suffering. When this happens in your own social circle, interacting with the epidemic becomes a profound existential experience.

Anyone who has gone through this is touched in a way that changes their life forever. My life since AIDS is totally different from what it was before AIDS. There’s a feeling of transformation when you’re affected very directly, very immediately by the epidemic, during that first phase of extreme suffering – which doesn’t mean that there’s no suffering today; there is, but at the time the suffering was right in your face. People were affected in many different ways. Some developed a more personal and less political involvement. Others had a more political and less personal connection. Still others had a more intellectual involvement. And some created a kind of barrier and denied the epidemic’s existence...

For me, AIDS was part of my innermost circle. I lived the experience of caring for sick people, living with people that were falling ill, often in terrible, difficult ways full of suffering. And it became such a total experience that I built my life around the epidemic. It was through the struggle in political action and as a researcher – I did my PhD in anthropology and sociology, and I was one of the first people in the world to embrace AIDS research. I recently...
I recently completed 35 years as a researcher, studying and writing about the epidemic and fighting AIDS. ABIA has been a crucial space in this sense, because it has never been an academic institution, but has always conducted research and studied the issue to act politically on the epidemic.

ABIA – How was Brazil’s response at the time? You mentioned that you participated from the beginning, since the first years of the epidemic in the country. How was the Brazilian response?

PARKER – The Brazilian response, as in many other places, emerged mostly from the grassroots, not from central governments. In the early years of the epidemic, central governments basically ignored its existence and did nothing. But the affected communities at local level, that is, at society’s grassroots, really mobilized in those early years. Health programs in some municipalities and states also mobilized.

The first AIDS program in Brazil was set up in São Paulo, I think in 1984 or maybe 1983. It was when representatives of the gay community went to people at the São Paulo Health Department, and this was repeated in several other states. The Ministry of Health only started to move, if I’m not mistaken, around 1986-87, which was also when the World Health Organization in Geneva began to link with various countries to set up programs, but it was after this experience that already existed in Brazil at the state level, at the municipal level. The first government program appeared more or less at the same time as ABIA in 1986-87.

The first NGO to be founded was the Group to Support AIDS Prevention (GAPA/SP), in 1985. ABIA was probably the second. I’m not sure of the date, because there were meetings starting to discuss ABIA before it was legally incorporated. The legal incorporation of ABIA as an institution was in 1987. That was when almost everything began. And the government initiatives, especially at the federal level, were still lukewarm and conservative. We were living the time of re-democratization in Brazil, with the Campaign for Direct Elections. Civil society organizations played a key role – and ABIA was a leader in this, but certainly not the only one.

– to pressure the state apparatus and the federal, state, and municipal governments to improve their work in the fight against discrimination, among other issues. And it was this pressure by civil society that pushed things forward. Government responses improved little by little. But what is known today as a success story was largely very timid and very bad in the 1980s. São Paulo always led the field of government programs, but Rio de Janeiro was very weak, because the issue simply didn’t interest the local politicians at the time.

ABIA – What marked you in those early years? You’ve already mentioned your personal perspective, but we’d like you to say more about your political point of view, mainly based on the experiences with mobilization in some states. What had the greatest impact on you?

PARKER – Looking back on those years, what amazes me the most is to remember how vibrant the mobilization of the nongovernmental organizations was, although they were very few in number. There were maybe 30 organizations at the time. There were organizations working more with care for people living with HIV. For example, in Rio de Janeiro, Grupo Pela Vidda/RJ (Group for Life/RJ) was the first organization for people living with HIV in Brazil. It started as a project inside ABIA. It was Daniel, when he was diagnosed, who gathered some seropositive friends together and talked about the need to have an organization to work with issues of HIV-positive people and not with AIDS as a whole. That was how Grupo Pela VIDDAA/RJ came about in 1989. I was at the Ford Foundation as a consultant and was in charge of
the funding for Grupo Pela VIDDA/RJ as one of ABIA’s projects. Grupo Pela VIDDA/RJ later created its own bylaws and became an independent organization.

Other organizations like ABIA played what was probably a broader role. At ABIA, for example, there were seropositive people, but the institution also fostered dialogue with society as a whole. And it had a unique characteristic which was to reflect on the epidemic, to work with concepts, and to reflect on which political strategies to adopt. ABIA did this not as a government program. It worked to create bridges between government and academic institutions, between health services staff, activists, and people in the communities.

Much of what I believe I know today about the epidemic, I learned in those first years with the NGOs, with people like Daniel and Betinho and other activists. For example, it was Herbert Daniel who taught me to think conceptually about AIDS as an epidemic with social determinants. He was the first one to point out in the early writings at ABIA that AIDS moves in society’s fissures, in social conflicts and inequalities, and spreads through these social tensions and fractures. Over the years, ABIA drew upon such concepts as epidemiology without numbers and cultural activism – using art to politicize, educate, and communicate. Other concepts were developed, like structural violence and vulnerability, that ABIA disseminated together with researchers from the Nucleus for Studies on AIDS Prevention at the University of São Paulo (Nepaids/USP). We wanted to raise the debate in Brazil’s classrooms and seminars, to create a space for exchanges between different sectors, activists, researchers, health professionals, administrators, and to promote an interdisciplinary and intersectoral discussion. It was through Betinho, Daniel, and their peers that we promoted the idea of health and human rights and the concept of human rights as a way of confronting AIDS. The first person in the whole world that I met who spoke of human rights and AIDS was Betinho, when he gave a talk at the School of Law at the University of São Paulo, in 1987.

ABIA and the other organizations offered what I see as the ethical and political foundations to build a response to the epidemic. Some of these new ideas were associated with Brazil’s health reform tradition. These principles were developed in such a way that the 1988 Constitution incorporated health as a fundamental right and the comprehensive nature of the Unified National Health System (SUS) as a basic principle for integrating prevention and treatment. Other AIDS issues added to this, like human rights and the struggle against intolerance, stigma, and discrimination. After the Collor government was overthrown and democratic government administrations were formed, the Brazilian state achieved sufficient democratic maturity to incorporate these ideas originating from civil society into the governmental sphere. This was the golden age of the Brazilian response — from the mid-1990s to 2000. And we truly moved forward for some time in a very positive way. Going back to one of our first questions: that was what made this space so important, so gratifying, so meaningful for me. To be there, to be part of this was a privilege. I think I learned more in those years than in all my life about what it means to build a true response to the AIDS epidemic.

**ABIA – How was the interaction between you, Betinho, and Daniel at the time?**

**PARKER** – We should remember that both Betinho and Daniel had returned to Brazil after amnesty, that is, from exile. Betinho returned to Brazil with a project to mobilize civil society in the country’s re-democratization. He founded the Brazilian Institute of Social and Economic Analyses (IBASE) for this work. And when he and his brothers Henfil and Chico Mário were diagnosed with HIV in the mid-1980s, he was impelled to create ABIA. The idea of working with re-democratization was the point of departure for ABIA, which proposed to democratize information. Betinho was outraged by the lack of government action to inform the Brazilian people about what was happening, to mobilize, hold campaigns against the clandestine blood market, and all the other measures that were needed at the time to tackle the epidemic. In Betinho’s vision, ABIA embodied this idea of an interdisciplinary association to unite people from different fields of knowledge. The only way was to confront all dimensions of the epidemic with an interdisciplinary approach.

Meanwhile, Herbert Daniel had returned to Brazil with a different project in mind: to work on forming new political parties and try to act politically to rebuild party politics in the country. He played an important role in the Green Party and partisan mobilization. But despite these differences, Betinho and Daniel had an interesting intellectual
partnership: one complemented the other, which was crucial for ABIA’s development. Betinho didn’t work every day at ABIA. He worked at IBASE. He was the president of ABIA, but the idea was always that ABIA should have a team that would run the daily work, with Betinho providing backup. Daniel was part of the ABIA staff, with Silvia Ramos, Walter Almeida, Ranulfo Cardoso, and several others. At the time I was a member of the Advisory Board of ABIA, I believe since 1989. I only got involved more actively in ABIA in 1991. In 1992, Betinho asked me to take over as executive director of ABIA. Daniel was already very ill and died in March that year. I served as executive coordinator until 1995. I later joined the Board of ABIA. When Betinho died in 1997, the vice-president at the time was Sonia Corrêa. I was elected president of ABIA in 1998. I’m the second president of the institution after Betinho.

**ABIA – Tell us a little more about your relations with Betinho and Daniel. How would you define your friendship?**

**PARKER** – Daniel and Betinho, despite many similarities, were extremally different people, and my relationship with the two was also very different. Since Betinho was older, from another generation, I saw him as a kind of father figure. My image of him was someone that I’d like to be when I grew up. Betinho was simply a sensational person, one-of-a-kind. Daniel on the other hand was from my generation. We were both gay. Our partners were friends. My relationship with Daniel was more as a friend and coworker. When he fell sick, he had several papers that he had committed himself to write. Since he wasn’t in any condition to finish, he asked me to take over these papers. But we decided to write them together. From 1989 until his death in early 1992, we had this close collaboration. We worked together, and I dived into the papers with him. Daniel was snatched away from us too early by the epidemic, at the peak of his creative capacity. I was left with his unfinished writings, but I wasn’t able to publish them because they were too dispersed to do it. Meanwhile, Betinho, until his death, was physically quite absent from ABIA because of the various campaigns he was heading, like Brazil’s nationwide campaign against hunger. But he was still there as a kind of moral compass. To this day, for us who the older members of ABIA, both Daniel and Betinho in their different ways are this compass. We measure what we do, based on what they would think or what they would do. At ABIA, not a day goes by without thinking of them, at least for those of us who were at the institution at the time. The legacy of Betinho and Daniel has had a profound influence in these 20, 25 years since they left us.

**ABIA – You mentioned that not a day goes by without thinking of these two great names in AIDS. What lessons did these two icons leave for the response to AIDS today? What lessons are present in daily life at ABIA?**

**PARKER** – With all the changes in the epidemic today, including more effective treatment, new biomedical forms of prevention, and all the novelties that have been implemented, I’m convinced that none of them is worth anything without these ethical and political principles I mentioned. Today we have “combination prevention”, but without the prevention literacy that helps us to think about how we’re going to implement it, it’s just knowledge set aside on the shelf without being used and with no efficacy in people’s real lives. It’s essential to have strategies to use these new methods that are now available.

In this sense, those early years are still like guiding threads on how to work. And if we don’t reclaim and respect this history, no path will lead us anywhere. The approaches of governments, unfortunately in Brazil (and in many other places in the world), have been to try to solve things with techniques, technologically, and with the technocrat of the hour in charge. This means losing the most important part of the legacy left by the first decade of political activism and mobilization. It’s true that some
benefits have been achieved, but lacking efficacy in their implementation. That’s what happened in Brazil in the last decade, when we threw political courage out the window. When the politicians in Brasília began to give in to conservatives, to the religious caucus, they threw out the progressive political stance that had guided the response to the epidemic. The government began to give ground and march backwards. Today we’re living a reality with new drugs and new biomedical methods for prevention. But we’re facing an epidemic that’s getting worse rather than better, because we lack direction to act. We don’t have a strategy to act, because we’re ignoring the successful experience from the past to guide us.

ABIA – You’ve already mentioned institutions – one of them was even born right here in ABIA – that were dedicated exclusively to people living with HIV and AIDS. ABIA takes a broader approach, but its work also has a direct impact on the lives of people living with HIV and AIDS. Can you tell us a little more about this experience over the course of these 30 years?

PARKER – The starting point for answering this question is the concept of solidarity. This concept was addressed very well by the ABIA leadership in the first decade of the epidemic. And it is still a way of working with the epidemic that characterizes ABIA and other NGOs doing similar work. It was the commitment to solidarity that ABIA always practiced with people directly affected by HIV that made the institution a source of inspiration and consolidated our image as a space that contributes to the experience of people living with HIV in Brazil. ABIA’s Board of Directors includes seropositive people, and a significant share of the staff is living with HIV. We cultivate a commitment to solidarity and ensure a space where people with and without HIV work together to deal with the epidemic. I believe that we continue to make an important contribution to people living with HIV and the organizations which, more than ABIA, work specifically to serve seropositive people. Any policy, response, or action related to AIDS should ask the question: how will this affect people living with HIV? This should be the underlying reason for any work with the epidemic. ABIA aims to gather and build a collective response. And for this to be effective, you have to know the impact that any given action will have on the lives of people living with HIV.

ABIA – And from the more political point of view, which major gains or highlights would you list in ABIA’s contribution to building this response to the epidemic?

PARKER – It’s important to say that ABIA has never done anything alone. We’ve always worked with other partner organizations, and these have been highly successful moments in our collective struggle, in which I feel that ABIA has played an important role. An example was the campaign against the commercial exploitation of blood transfusions in the 1980s, which may have been the most successful action in confronting the epidemic in the history of AIDS. In the 1990s, we experienced a lot of clashes to build a much larger program in the federal government (I worked for a time as head of the AIDS prevention unit in the Ministry of Health), and later various people from ABIA worked as consultants, helping draft the World Bank loan project for Brazil. So, ABIA contributed directly to building Brazil’s successful AIDS Program.

Over the years, the institution kept up its watchdog role, to keep things on track. Such mobilization definitely included the campaign for passage of the Antiretrovirals Law in 1996 and the process of...
forming the Working Group on Intellectual Property. The Working Group has played a crucial role in the struggle to guarantee access to medicines from the financial point of view, against the capitalist system and against the patent system that excludes the people that actually need these drugs. In 2007, we played a crucial role in what I consider the height of the Brazilian response: the compulsory licensing of efavirenz.

I would also emphasize the fight against stigma and discrimination and for the rights in relation to sexuality, gender, and non-normative populations like sex workers, gay people, other men who have sex with men, young people with the right to be sexually active. Today, these and other issues are addressed more clearly in our “Project on Sexual Diversity, Health, and Rights among Youth”, financed by the MAC AIDS Fund. ABIA also began collaboration with feminist organizations to work with the AIDS issue and women and reproductive rights. ABIA serves as the secretariat for Sexuality Policy Watch (SPW), which works with sexuality policy issues in the international arena and in Brazil. These lines of action – in the struggle for access to treatment, the struggle for the rights of people living with HIV and people in various situations affected by the epidemic – have been constants at ABIA. Another basic line of action in the struggle is prevention. Prevention literacy has been a key focus of our work in recent years. The concept emerged from “treatment literacy”, when new treatments were created. We apply the idea to the field of prevention, another constant contribution by ABIA.

ABIA – Prevention literacy, which you’ve mentioned, is one of the most innovative aspects of a proposal for a response to the epidemic. Tells us why it’s so innovative and crucial.

PARKER – Prevention literacy is innovative precisely because it draws on the past. It means a return to ABIA’s roots in the 1980s. We need to go back to the understanding of confronting the epidemic not merely as a technical or technological issue, but as a fundamentally political issue. Prevention literacy draws on our experience with implementing programs for access to medicines, like treatment literacy, in which people needed access to knowledge and empowerment to take control of their treatment. In prevention, this means assuming that we’re not going to simply accept the “use condoms” mantra. Prevention should be on our terms, with our knowledge and our control over our lives in the context of prevention. In these menacing times in Brazil, to build a response to the epidemic, we need to seek inspiration in political mobilization, in the defense of the affected communities, and in the resistance, without which there can be no success.

ABIA – ABIA does intense international work and interesting and important networking. What would you highlight in this work?

PARKER – Definitely, ABIA is and always has been one of the most active organizations in this interface with international action. ABIA was one of the founding NGOs of the International Council of AIDS Service Organizations (ICASE), whose Secretariat is in Canada. It was also one of the founders of the Latin American and Caribbean Council of AIDS Service Organizations (LACCASO). ABIA interacted with, participated in, and worked with the Global Program on AIDS of the World Health Organization (WHO) and the Joint United Nations Program on HIV/AIDS (UNAIDS). This interface was important for sharing the lessons from the Brazilian experience with the rest of the world, besides bringing home the innovations and ideas that might fit the reality we work with in Brazil. It is essential to ensure that Brazil’s contributions are known abroad, and it is also crucial for us to participate in the global movement dealing with the epidemic. And to realize that it’s not only here in Brazil that we have to act, but also in various places simultaneously. This makes ABIA outstanding, and I consider it a special and important contribution by ABIA.

ABIA – What prospects does ABIA imagine in the next 10 years on this path, in this struggle?

PARKER – I know one thing: we have not reached the end of AIDS. I have spoken a lot about this in recent times, and I think it’s a fallacy to announce that we’re nearing the end of the epidemic, that we only have to move just a little more, and that everything will be solved by 2030. But in 2027, we won’t be saying that in three years AIDS will have reached the end. I do hope that we’ll have many successes in dealing with the epidemic with new drugs, maybe with vaccines... just as Betinho always believed, that someday a cure would come. But I
also know that effective drugs have been available for more than 20 years, drugs that could control the epidemic, but today, in 2017, nearly 50% of people in the world who need them don’t have access to these drugs. The end-of-AIDS narrative is a kind of smokescreen, since it hides the millions of people and their suffering, the people that have no access to treatment. It also hides the suffering of people who have access but live in poor countries that only provide first-generation drugs with a lot of side effects and negative consequences. These people also suffer and continue to die.

In Brazil, supposedly with universal access to antiretroviral medicines, we have an absolutely unacceptable number of people that still die of AIDS. These mortality rates are also hidden by the end-of-AIDS discourse. And no one has a guaranteed right to prevention. Pressure by civil society for access to treatment may transform it into a fundamental right for all citizens. But we have still not convinced people that everyone also needs the right to prevention. Prevention is still seen as a privilege. Just look at the small number of people that the Brazilian government finally announced will have access to pre-exposure prophylaxis (PrEP). The end-of-AIDS narrative hides the fact that prevention is still not viewed as a right. Let’s assume that the cure for AIDS is announced in a few days – and I do hope we’ll hear this news. It’ll take a long time – as it has taken two decades until now – for 50% of the people that need treatment, to have access to the cure. This happens because of the world’s existing inequalities. We’ll never get anywhere without dealing with this. Over the next 10 years, we’ll continue to deal with this struggle with progress, I hope. I think we should prepare for a long, hard battle. We need to be realistic about what we’ve achieved so far and about what needs to be done to travel the rest of the way until we reach a future in which AIDS is controlled.
ABIA and life with HIV and AIDS in Brazil

ABIA’s 30 years, life with HIV and AIDS has been a priority in the association’s policies and actions. In fact, the focus on life with HIV began with founder and president Herbert de Souza, Betinho, who already lived publicly with HIV when ABIA was founded in 1987. Importantly, Betinho chaired ABIA until his death in 1997.

Unlike other nongovernmental organizations dedicated to people living with HIV and AIDS in the late 1980s, ABIA did not work directly with care for patients or self-help. From the beginning, ABIA focused on action for the development of fair public policies for people living with HIV and AIDS, as well as the mobilization of seropositive people to organize and assume the role of citizens and protagonists in their treatment, shaping the response to the HIV/AIDS epidemic in Brazil.

One of the first outstanding initiatives at the time was ABIA’s lobbying for passage of Brazil’s so-called “Blood Law” (or Safe Blood Transusions Act) in 1988. Until the law entered into force, blood transfusions in Brazil were not subject to standard public health controls and could be marketed freely by blood banks. The law’s enactment was crucial for curbing HIV transmission via blood transfusions and was a major victory for the Brazilian hemophiliac population, who ran the risk of being decimated by HIV in case transfusions continued uncontrolled. Another key initiative was the legal action against a hospital administered by the Catholic Church, which had refused to admit a seropositive child claiming lack of conditions (the child died soon afterward). ABIA lost the case, but it became emblematic nevertheless by calling attention to the stigma facing people living with HIV, to the point of being denied treatment in public and private hospitals.

The year 1989 was especially important. ABIA’s coordinators already included Herbert Daniel, writer; former guerrilla fighter, and already a national leader on issues related to sexuality and civil rights. Early that year Daniel had already been diagnosed with HIV, and from then on this reinforced his brilliant activism and writing, which were fundamental in the creation of a discourse to counter the discourse of fear, stigma, prejudices,
and discrimination, especially against people living with HIV and AIDS and their families and friends.

The basis for this alternative discourse was *solidarity*, already proposed by Herbert de Souza as the first principle in the fight against HIV. Far from invoking compassion, in the ideals defended by the two Herber.ts, *solidarity* meant participation, mobilization, leadership, empathy (the capacity to put one’s self in the other’s position), respect for difference, and equal rights.

Based on *solidarity*, Daniel proposed concepts like *civil death* (1989), which denounced the stigma, violation of rights, and discrimination that people living with HIV still suffer. Civil death emphasized that seropositive persons suffered a social death first, even before their clinical death from AIDS, with the denial of basic rights like housing and employment and the right to come and go, among others. The concept was important for redefining people living with AIDS as citizens in full exercise of their rights, and not only as patients depending on care from others and stripped of their citizenship.

The concepts of *civil death* and *solidarity* both gained a material basis in the NGO Grupo Pela VIDDA/Rio de Janeiro (Valorization, Integration, and Dignity of Persons with AIDS), founded by Herbert Daniel himself in May 1989, at ABIA’s headquarters, with the institution’s full support. When they founded Grupo Pela VIDDA/RJ, Daniel and his collaborators developed a concept of life with HIV beyond serological status; they contended that all of humankind was living with HIV, since everyone could potentially be infected by the virus, given the epidemic’s planetary dimensions, in addition to the human rights violations that affected not only seropositive individuals but all humans. In the mid-1990s, this concept of life with HIV was questioned by other movements of people living with AIDS, but without denying the effect of encouraging and empowering solidarity as the result of Herbert Daniel’s ideas.

That same year, the recently founded Rio Solidarity Network convened local AIDS NGOs at the ABIA headquarters under Daniel’s leadership and drafted the Declaration of the Fundamental Rights of Persons Living with HIV and AIDS, passed unanimously by the 50 organizations participating in the 2nd National Meeting of AIDS NGOs in October 1989, in Porto Alegre, Rio Grande do Sul. In the document, seropositivity was no longer merely a clinical issue or a stigma in a person’s lives; rather, it was now projected as an issue of citizenship and human rights. And from then on, the Declaration guided the work not only by civil society, but also by health professionals, researchers, and administrators in the following years, characterizing the relationship with civil society.
death that affects people living with HIV and AIDS.

Daniel’s writings on AIDS feature those gathered in the books *Life Before Death* (1989) and *AIDS: The Third Epidemic* (1991, co-authored with Richard Parker). In the former, articles like “You Never Forget Your First AZT” (1989) were a milestone for mobilization of people living with HIV to address the issue of access to medicines. The latter book elaborates on the concept of the Third Epidemic, pointing to the alarmism that caused fear, discrimination, and prejudice, with effects as deadly as the virus itself. Such concepts still support mobilization and solidarity today, demonstrating the vigor with which they were first conceived.

In 1991, to empower people living with HIV in the response to AIDS, the partnership between ABIA and Grupo Pela VIDDA/RJ resulted in the 1st National Meeting of People Living with HIV and AIDS, the editions of which are still held today as one of the most important events organized by and for people living with HIV and AIDS. The meeting features an inter-sector and interdisciplinary discussion of the main issues related to life with HIV and AIDS, including rights, clinical issues, sexuality, gender, and others.

Daniel’s death in March 1992 was a huge loss for ABIA and Grupo Pela VIDDA/RJ, but ABIA continued to co-organize “Vivendo”, or “Living” (as the National Meetings of People Living with HIV/AIDS came to be known) until 1995.

Challenging the fatalism, fear, and stigma that still permeated the discourses on AIDS in 1994, Betinho proposed the concept of a cure for AIDS. It was during the early stages of antiretroviral therapy, which only revolutionized life with HIV two years later. At that time, living with HIV was still tantamount to dying with HIV, since the possibilities were still very limited. The concept of a cure for AIDS was thus daring, basically saying that the fact that no cure had been discovered did not mean that none existed, or that a cure wouldn’t be discovered some day.

Thus, it was worth the effort to participate with solidarity, mobilization, and political lobbying for a cure to be achieved. It was crucial to overcome immobilism and fatalist ideas, as well as the division between healthy and sick, infected and uninfected, to make a break with the equation AIDS = death, which still dominated various government campaigns at the time.

In the following years, these concepts came to guide ABIA’s actions and policies for the mobilization of seropositive people to guarantee their civil and human rights. With this spirit, even after Betinho’s death in 1997, ABIA continued to work with people living with HIV. Importantly, the emphasis on the struggle for universal access to antiretroviral drugs gained a new meaning starting in 1996. That was the year of the 11th International AIDS Conference in Vancouver, Canada, where it was announced that antiretrovirals, previously used as monotherapy, could now be combined in dual or triple therapies to control HIV infection in the human body. This finding in rigorous clinical trials turned AIDS into a treatable disease, which helped break with its stigma as a fatal disease and its association with death.

Despite this extremely important milestone, there were other challenges, since access to antiretrovirals involved new trade regulations on intellectual and industrial property, making these drugs unaffordable for most people in Brazil and the world. The struggle for universal access now involved the struggle to reduce prices, to denounce abusive prices resulting from the lack of regulations.
that respect public health interests rather than just the commercial interests of the large multinational corporations with the monopoly rights to market these drugs.

From the beginning, ABIA monitored the research and access to the first antiretroviral drugs and co-sponsored legal action for access to them in Brazil, working intensely in this field together with organizations of seropositive people, international NGOs, and some public policymakers. This dedicated work resulted in the founding of the Working Group on Intellectual Property (GTPI in Portuguese) within the framework of the Brazilian Network for the Integration of Peoples and still coordinated by ABIA today. With intense participation by individuals and organizations of people living with HIV and AIDS, the Working Group aims to expose economic abuses related to AIDS drugs, conducts opposition proceedings to invalid patents, and conducts educational activities on treatment for persons living with HIV and AIDS and activists, among other attributions and struggles which are addressed in greater depth in another article in this publication.

Starting in 1996, the possibility of effective AIDS treatment also raised a series of new challenges for life with HIV, which not only gained in terms of the possibility of longer life, but also in the search for quality of life. The challenges included issues related to sexuality, side effects and adverse reactions associated with antiretrovirals, reproduction, treatment adherence, and others. Since then, ABIA maintains a free 24X7 counseling service for seropositive persons, especially those with a recent diagnosis, and who need such attention. The 2000s, ABIA conducted a series of pioneering projects devoted to social research to learn about the conjugal life, sexuality, reproductive health, concerns and aspirations, and life projects of serodiscordant couples (homosexual and heterosexual) in order to work with prevention and treatment adherence. Other social research addressed the levels of treatment adherence with antiretrovirals in homosexual and heterosexual persons (men and women) and the challenges for expanding and maintaining them.

In the latter half of the 2000s, ABIA participated in governmental and nongovernmental initiatives to work with so-called HIV-positive prevention, involving tips on prevention of opportunistic infections, safer sex, quality of life for persons living with HIV and AIDS, and promotion of human rights, among other issues. The concept, in the age of combination antiretroviral therapy and the resulting extension of life with HIV, gained new relevance in public policies. However, the concept itself had always been present in ABIA’s...
work, which had always devoted a wide range of publications and videos to life with HIV and AIDS. Publications such as *Living life positively* (1989, in partnership with Grupo Pela VIDDA/RJ), with information on HIV testing, diagnosis, and life with HIV; the revolutionary video *Love, Life, Live!* (1989, directed by Monica Teixeira), starring people living with HIV and AIDS and their families in the pre-antiretroviral age; and the documentary *Masks* (2012, directed by Vagner de Almeida), discussing the sexuality of young people living with HIV and AIDS. These are examples of projects that showed different aspects of life with HIV and aimed to fight stigmas, value life, and contribute to avoiding not only illness, but also invisibility and civil death.

Beginning in 2008, studies by ABIA discussed the prejudices that still existed in the gay and MSM population concerning affective relationships with people living with HIV and AIDS, leading ABIA to dedicate a segment of its HIV/AIDS prevention program for MSM to deal with the reality of seropositive homosexual men. This initiative involved working with such issues as corporeality and adverse drug effects, sexuality, and integration and social participation.

One of the most innovative results from the late 2000s included launches of such publications as *Tudo em cima* (2012), a booklet with tips for preventing adverse effects from antiretrovirals, like physical and metabolic changes caused by lipodystrophy and dyslipidemia. *Combination Prevention* (2010 and 2016) was another pioneering publication on new prevention technologies and methods that were starting to be incorporated into the policies and actions in this area. Two recent strategies, *Treatment as Prevention and Test and Treat*, both adopted as public policy in Brazil in 2013, are directly relevant to people living with HIV and AIDS.

It would be impossible in this brief article to provide details on all the initiatives by ABIA for and with people living with HIV and AIDS. Our aim is much more to revisit the principles and concepts that guided these initiatives and that prevail to this day in the institution. Some of the examples mentioned above show the fields in which they were developed, some pioneering, and definitely point to the complexity of life with HIV, despite the discourses that appear to reduce it to the use of medicines and its clinical dimensions, and that can reduce the person living with HIV and AIDS to nothing more than a patient, overlooking a whole other range of social and collective dimensions. The principles and concepts discussed here, as well as the initiatives described, were conceived and developed by people living with HIV and AIDS. This deserves emphasis here, since it’s about the experience of the people themselves as protagonists, and who must be included in the health policies and actions destined for them. Reaffirming an international principle of the response to AIDS, ABIA’s history with regard to living with HIV and AIDS is dedicated to the work for and with this population and continues to be founded on the principle of solidarity, the basis for all the work developed by the institution. ■
Our struggle is for respect, for the right to medicines

Organized civil society’s leadership in the response to the HIV/AIDS epidemic is a well-known fact, confirmed by national and international researchers and authorities. This recognition reinforces the understanding that without civil society’s participation in prevention, care, the promotion of public health and human rights, and other areas, the response to HIV would never have achieved such positive results in nearly four decades. Such recognition especially confirms the very early perception by sociologist Herbert de Souza (Brazil’s “Betinho”), when he said that the epidemic was not only biological, but also social, and as such required a response by the whole of society.

This perception has been crucial for orienting civil society’s interventions in various areas, including access to medicines, seeking to develop an autonomous discourse legitimized by the experience of persons affected by the disease, and the understanding of the social meaning of economic policy for medicines and its spinoffs in the context of public health policy. The AIDS epidemic emerged in the 1980s and 1990s, when Brazil was experiencing intense economic liberalization in the midst of euphoria over the country’s re-democratization.

In this context dominated by the discourse of modernity and the triumph of capitalism, AIDS presented the world with a virtually premodern disease phenomenon. When an AIDS diagnosis was still a death sentence, the first antiretroviral drugs appeared, capable of controlling the epidemic. In the 1980s, especially in the Northern Hemisphere, where the first AIDS drugs were developed, groups of activists took to the streets and led public debates to demand more investment in the development of new drugs and changes in research rules. In the United States, these activist groups succeeded in shortening by half the turnaround time for new drugs to reach patients. However, the extremely high prices set by the transnational corporations marketing these medicines created a macabre divide, with a purely
The political formula linking solidarity, language for mobilization, and the defense of universal and comprehensive healthcare, fundamental characteristics of the AIDS movement, and the technical knowledge on patents spawned a single forum in the struggle to guarantee the right to health in the face of transnational corporations’ greed. ABIA has always mobilized in defense of health rights and universal access to medicines.

The political formula linking solidarity, language for mobilization, and the defense of universal and comprehensive healthcare, fundamental characteristics of the AIDS movement, and the technical knowledge on patents spawned a singular forum in the struggle to guarantee the right to health in the face of transnational corporations’ greed. ABIA has spearheaded this movement since 2002, heading the Working Group on Intellectual Property (GTPI) of the Brazilian Network for the Integration of Peoples. The political formula linking solidarity, language for mobilization, and the defense of universal and comprehensive healthcare, fundamental characteristics of the AIDS movement, and the technical knowledge on patents spawned a singular forum in the struggle to guarantee the right to health in the face of transnational corporations’ greed.

The third innovation was the wager on innovative repertoires for grassroots mobilization at a time when intellectuals were proclaiming the demise of political struggle and the end of history. Activists thus explored the contradictions and nefarious consequences of the neoliberal order itself. In Brazil, for example, activists sought to maximize equity in health in the midst of a neoliberal state, rebuilding notions of democracy and ethics.
In various countries of the Global South, invisible market agents were identified and exposed in mass protests, and many attempts to make politics migrate to legal control and trade rules were countered with strategies of civil disobedience, strategic litigation, and intensive technical training by activists. The latter literally “occupied” the legal sphere to prevent the depoliticization of key debates on healthcare entitlement. In Brazil, for example, ABIA/GTPI spearheaded a pioneering case in the world, claiming compulsory licensing (known as “patent breaking”) through a class action suit. Not to mention the countless patent oppositions filed by ABIA/GTPI, consisting of technical arguments pointing to the nullity of certain patent applications, in order for the technologies covered by them to reach the public domain. These opposition proceedings are frequently cited in the patent denial rulings and may soon mean a huge contribution to transferring Truvada (an important tool for HIV/AIDS prevention) into the public domain.

These three lines of action have turned activism for access to medicines into a phenomenon that has reversed a process of extreme exclusion, through robust citizenship practices. This is the very reason by which the AIDS struggle has always been marked by the struggle for treatments, first to guarantee a process of research and development of innovations at the necessary pace, and later to guarantee global equity in the distribution of the fruits of scientific progress.

It was the deep understanding by activists and the communities most affected by AIDS that triggered a movement to promote health and dignity, ramping up the pace for researchers and regulatory agencies. “This has been a movement that came together in anger; that thirsts for justice, that is fundamentally about unleashing the power of human solidarity,” said World Bank President Jim Kim in his opening speech to the World AIDS Conference in Washington D.C. in July 2012, with vigorous praise for AIDS activists.

When triple therapy, announced to the world in 1996, made AIDS a treatable condition in developed countries, the focus shifted to the periphery of the capitalist system, where an ideological struggle began that has still not been resolved, concerning drug patents. It became evident that science, but not the pharmaceutical corporations, made living with AIDS possible.

The TRIPS agreement, then recently signed, establishing global rules for patents, placed medicines on an equal footing with other commercial products, thus allowing monopolies on their circulation. Such monopolies were defended at all costs by the pharmaceutical companies, even in the countries where the companies extract virtually no profit, due to the local populations’ extreme poverty. Defending pharmaceutical patents became an ideological purpose whose consequence was the exclusion of entire populations from access to medicines, precisely those populations most affected by the epidemic.

It was exactly these people, considered too poor to be cured, who succeeded in organizing themselves to understand this complex system and to fight it from within, creating the cracks by which the production of generics became possible and that led to the acknowledgement, at the highest political level, that the right to health cannot be outweighed by trade rules.

These episodes show that the struggle for access to medicines has always been led by civil society, and not by governments or international agencies. It is in fact a bottom-up struggle, without which we would not have reached today, in 2017, with 19 million persons in treatment for HIV/AIDS.

But it is time for us to move further. If in the past we struggled within the neoliberal paradigm, within the framework of the TRIPS Agreement, using health safeguards to guarantee the right to health, we need to go further.
It is time to say, once and for all, that the populations’ right to health is more important than the privileges and monopolies of pharmaceutical corporations. At the peak of neoliberalism, people the world over are mobilizing to dismantle corporate power, starting from various experiences of violations of rights. What is clear after two decades of the TRIPS Agreement is that the violation of the human right to health is inherent to the pharmaceutical corporations’ business model.

It is necessary to put a stop to the impunity that allows the American pharmaceutical company Gilead Sciences to charge a price for sofosbuvir (a drug that cures hepatitis C) that cruelly prevents millions of people the world over from achieving immediate cure; that allows Interfarma in Brazil, Novartis in India, and CAEM in Argentina, among others, to remove from sovereign national laws the safeguards for the defense of health; and that allows fatal imbalances in the management of medical innovations. It is thus urgent to oppose the architecture of impunity that allows pharmaceutical corporations to draw the line between those who live and those who die. A first step in this direction is to reframe the debate on the states’ obligation to acknowledge drug patents, since it is a system that has already proven failed and dysfunctional, that threatens the survival of entire populations and thus needs to be overcome.

This should be our utopia. As we pursue this ideal, we will struggle daily to end each monopoly that prevents patients from having access to medicines in Brazil and in the Global South as a whole.

This should be our utopia. While we make our way toward this ideal, we will struggle on a daily basis to end every monopoly that impedes patients from having access to medicines in Brazil and the Global South.
The Path to Solidarity is Knowing How to Listen

Spontaneously welcoming and embracing countless people recently diagnosed with HIV has been a constant practice at ABIA throughout the institution’s 30 years. Motivated by the principle of solidarity that has inspired the response to AIDS since the 1980s, ABIA seeks to awaken in people a way of welcoming, embracing, and listening to people’s demands and encouraging love for life in times of HIV and AIDS.

The history of solidarity in the HIV field is full of inspiring examples that have consolidated the concept of solidarity in response to the epidemic. When the epidemic was still surrounded by stigma and death, solidarity awakened love and life. Many lesbian women became involved in the cause, helping their friends, especially gay men affected by the epidemic in the 1980s, as well as the first sympathetic physicians that overcame fears to deal with patients that were totally shunned by most health professionals. Stories based on love for one’s neighbor and solidarity transformed people and consolidated their involvement in the cause.

Such solidarity sprang vigorously from organized civil society. Many inspiring acts came from NGOs that embraced the issue and spawned innovative action by civil society, like solidarity among peers or in “serodifferent” couples. Such action led to the process of building solidarity in health and health services – and became public policy in specialized services. At the time, a more technical approach was adopted, in the form of pre-and post-test counseling. Solidarity in services has an immeasurable impact in terms of valuing life and creating bonds. And it has positive repercussions on treatment adherence.

Since ABIA was founded, the institution has
welcomed and embraced demands (for example) related to information and orientation on how to prevent infection, besides encouraging decisions on what to do when one receives a positive HIV test result. ABIA is an open, safe space and an alternative to public health services, with a different interdisciplinary perspective, where HIV-infected people and those affected by the epidemic are able to explore feelings, express fears, have questions answered, and get oriented to make choices related to their future. For many, ABIA’s nongovernmental space is the first place they look to for information and orientation on living with and/or living in contact with HIV and AIDS.

Both solidarity and counseling are very special ways of “providing help”. In the epidemic’s context, they assume unique importance due to the stigma and prejudice that accompany HIV infection even today. At ABIA, we know that there can be no space for good counseling if people are not welcomed and embraced, allowing them to establish a relationship of trust, with no room for prescriptive norms, like “this is how it’s done, and this is what you should do”.

The demand for support and solidarity at ABIA almost always involves the need for more in-depth orientation and information that allow clearing up doubts and relieving anxieties, and often also as a space for help in the search for access and an opening in the health services to receive medical follow-up and treatment. Such solidarity, now one of the guidelines of Brazil’s National Policy for Humanization of Healthcare (PNH in Portuguese), found space in NGOs like ABIA as an ideal place for redefinition through the combination of welcoming, informing, and orienting (counseling) in response to the needs of citizens who are not welcomed by health services or do not feel welcome there.

ABIA assigns such importance to this issue that ABIA Bulletin n°. 57 in 2010 was devoted to the theme of Counseling, approached from the perspective of the importance of solidarity.

Solidarity at ABIA can include traditional counseling, while offering people the possibility of joining one of the institution’s projects where they can find group support.

We can cite projects and initiatives at ABIA as examples of pioneering work in this. The “CVRD Company Project”, for example, dealt with workplace solidarity, aiming to create and provide a safe place for seropositive employees to talk in a situation of vulnerability. The project also included company health staff and offered a favorable setting for dealing with issues related to HIV and AIDS and sexuality. It also encouraged an institutional policy of non-discrimination.

Another example was the initiative by ABIA to receive serodiscordant couples (now referred to as serodifferent). The project’s focus was to receive people in situations involving an amoros-
sexual relationship between people with different HIV serologies, and who had not been welcomed by health services. This initiative developed into a “Serodiscordant Couples’ Workshop” and the “Seminar on Conjugality and AIDS: Serodiscordance and Health Services”. It also generated the booklet “Serodiscordant Couples; tips for a healthy, safe, and happy life”.

In the 21st century, we continue to offer special, open solidarity as an alternative to that offered by the Unified Health System, which is based primarily on biomedical answers. There are persistent challenges for ensuring the quality of health services, challenges that definitely involve the importance of supportive care as a way to value such services. Some social initiatives such as online care have emerged in this new context of the “internet of things” and allow reinvigorating this practice. Virtual peer-to-peer and youtuber support networks have expanded, mobilizing information and creating new roles in the group support process.

The feeling of being able to help someone else in their time of despair, when everything seems hopeless, is beyond description. In some way, we all have the ability to help face the internal prejudices that manifest at this moment of the HIV diagnosis.

For ABIA, solidarity and support are one of the institution’s strategic activities. To celebrate these 30 years, we have established one day a week to welcome recently diagnosed people face-to-face. The institution thereby remains faithful to the principle of solidarity and the struggle for social justice.
ABIA 30 Years
of Struggle and
Solidarity