Introduction: “Blogging Positively”

The “Blogging Positively” Guide is the brainchild of bloggers seeking to address the HIV/AIDS pandemic in a meaningful way. Citizen media tools – including blogs, podcasts, and online photo and video sites – present powerful new opportunities for activists aiming to spread awareness and promote discussion about HIV/AIDS and its societal stigma.

There are many ways in which blogging is a valuable tool for discussions and activism around HIV/AIDS, including: 1) what you post is part of a permanent, stored record; 2) audiences are potentially global; 3) personal interactions take place at many levels, from the local to the international; 4) anonymity is possible, and not necessarily an impediment to influence; 5) replication and remixing make for creative storytelling; and 6) conversations can be both synchronous (real time) and asynchronous (across different time periods).

There are also some potential disadvantages to blogging that are important to keep in mind, including 1) the risk of spreading misinformation; 2) susceptibility to online or offline negative comments; and 3) the necessary access to a computer, Internet connection, and electricity.

In our research on HIV/AIDS blogging, we have discovered at least 200 bloggers worldwide, many living with HIV/AIDS, who regularly write about HIV/AIDS-related topics. Our interactive map (link below) lists bloggers we have identified, and we welcome additions to the directory.

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This guide has evolved in part through a series of chats attended in 2008 and 2009 by a wide-ranging group of people: veteran and novice bloggers; people from cities and rural areas; those from developed and developing countries; some with steady computer and Internet access, many with only minimal access; people who are HIV-positive, and those who are HIV-negative; those working in the HIV/AIDS field, and people working in other fields, such as technology, harm-reduction, the arts, and secondary education.

What we all have in common is a desire to learn more about how technology can be utilized to improve human health and well-being, and how citizen media might effectively address HIV/AIDS. We hope this labor of love will be helpful as you find your own voice and your own ways of coping with, challenging, and defeating HIV/AIDS. The title of the guide, coined by Kenyan blogger Daudi Were, thus has multiple meanings: We hope it will be useful for people infected and affected by HIV/AIDS, and that it will also be helpful to those who aim to spread more awareness about prevention, healthy living, and human rights.

What is Blogging?

The word “blog” is short for weblog and refers to a type of website that is updated chronologically. You can think of a blog just like email. Except, instead of sending an email to just one person, you are publishing the note on a website where it can be seen by anyone in the world with an Internet connection.

Most blogs allow for comments, enabling readers to ask questions or add their own opinions to what you publish. This is how a conversation begins - one person writes his or her opinion and then others add to the conversation. Some of the most popular weblogs receive over 100 comments every time something is published, but the vast majority of blogs are written for an audience of just a handful of readers with similar interests.

Why Blog about HIV/AIDS?

Personal stories are often a central focus of blogging. They can help inform and educate readers, enhance activism, and inspire change. Bloggers can tell the personal stories of individuals, rather than resorting to broad stereotypes or statistics.

Blogging about one’s HIV status or the challenges of living with HIV/AIDS can be empowering, both for the blogger and his or her readers. A blog can be a safe space that is usually free from discrimination. Someone applying for antiretroviral treatment, for example, might explain the process to others. Or that same person could create a digital “Memory Book” for families and loved ones to preserve family history and strengthen the bonds of those who remain.

Most people who blog about HIV/AIDS have education and prevention as primary goals. Some have a more

Blogging Anonymously

There are many reasons to blog under your real name, including credibility, honesty, and reputation. But some people live in places or under conditions where what they write could threaten their safety. For this reason, Global Voices has put together a guide on how to blog anonymously and hide your identity online.

Protect Human Rights

WITNESS Video Hub is a participatory website where anyone, anywhere can upload media related to human rights that can be used to create change. If you have witnessed police brutality, or any other kind of human rights abuse, and captured it on your cell phone or video camera, here is a way to safely and anonymously document what happened and help put an end to it.
Nata Village’s Ntwakgolo Support Group

Nearly one in four adults in Botswana is HIV-positive, and the United Nations has estimated that by 2010 more than 20 percent of all children in Botswana will be orphaned as a result of the HIV/AIDS epidemic. In the small rural village of Nata 20 activists are living openly with their HIV-positive status to confront the stigma that surrounds the pandemic.

In Setswana (the official language in Botswana), “Ntwakgolo” means “Great War,” an appropriate name for the battle being waged against HIV/AIDS in Nata. Members of the Ntwakgolo Support Group are among the first people to openly identify as HIV-positive within their communities. By their example, they are encouraging others to live more openly, too.

The Nata Village weblog began in 2006 when a tech-savvy traveler met a local HIV/AIDS educator in the rural Botswanan village. The blog has raised tens of thousands of dollars and is now sustained by local staff at the Nata AIDS and Orphan Trust.

http://is.gd/1B229 | http://is.gd/1B1Og

REPACTED

REPACTED was formed in 2001 to encourage young people to get involved with community development through participatory theater, awareness campaigns, peer education and counseling. REPACTED addresses HIV/AIDS, substance abuse, peace and conflict resolution, and sustainable development.

In 2008 they started the Youth Media Consultative Forum, which collects news and stories from communities in and around Nakuru, Kenya and posts them on the Internet, allowing local residents to show the true picture of their community. REPACTED has trained over 20 staff members and community leaders how to blog and produce multimedia content. Those who have already been trained are asked to reach out to 20 friends, including young people who are still gang members.

http://repacted.org
Contribute topics that both come from the heart and that also inspire discussion. This should help beginners relax. Though advanced aspects of blogging can be technically daunting, it is best to keep things simple, easy, and fun for new bloggers.

Encourage collaboration. Remind new bloggers to comment on the posts published by their peers. Sometimes it is also helpful to write a “guest column” on someone else’s blog. Many different bloggers can also contribute to one group blog, which encourages a sense of teamwork.

If you have time, start a blog yourself, and create links to the blogs of your students, or link their blogs to your already-existing blog. If you can find fellow teachers or facilitators who specialize in creative writing or storytelling, you might ask them to be of assistance. They may know techniques for getting people to relax and enjoy the creative process. They may also be more available than often-overworked health or service-organization personnel.

Schools and libraries might also have good human and/or technical resources.

Think about how to create more opportunities for those who are not Internet-fluent. In Uganda, the PeerLink project [http://www.geocities.com/peluli/index.htm] links learning about computers with learning about HIV/AIDS. Urban students, who tend to be computer savvy, are paired with young people in rural schools, who often lack both equipment and knowledge about computers, as well as Internet access.

The urban-based young people help their rural peers gain access to computer equipment and the Internet, and then give computer tutorials to the rural students. Both groups then engage in mutual learning about HIV/AIDS.

Q & A for Teachers or Facilitators

How can we encourage young people, women, people with disabilities, people living with HIV/AIDS, and others who often are marginalized? If people come to you, create a safe physical space for them to begin their blogging experience. Otherwise, do outreach to organizations working with these populations, promoting the idea of blogging as an empowering and educational tool.

How can we engage people living in rural areas to address HIV/AIDS using citizen media? The content published on blogs can be written, filmed, photographed, and recorded offline, then uploaded whenever Internet access is available. Other forms of citizen media — radio, mobile phones, and the arts — are also important tools.

How can we use media tools to form social movements for change? HIV/AIDS is both a personal and a public health challenge. Because of its wide-ranging impact on so many aspects of life and at so many levels of society, it is something around which a social movement can easily form. Bloggers might be encouraged to see their work linked to a larger whole, as new media connects groups locally, nationally, and around the world. Positive bloggers can connect with one another and also with other issues-based groups. Blogging can be equally effective in reaching out to those with little or no HIV/AIDS awareness — or those with a different perspective about the pandemic — to build bridges and promote dialogue.

How do we approach and involve institutions and health professionals? Blogging can be promoted as a form of therapy for their clients and staff, and institutions can be encouraged to blog about their successes, needs, and challenges. Some institutions and health professionals may be able to train new bloggers, and can provide educational materials for bloggers to convey HIV/AIDS-related information to others.

Institutions might provide access to the Internet, and bloggers in turn could form a corps of peer educators, working in tandem with the institution to improve personal and public health.

How can we promote and develop blogging so that it encourages people to see themselves as leaders? If each person understands that his or her blogging voice is unique and might inspire others to better understand the issue or to become active in addressing HIV/AIDS, they will hopefully have incentive to continue speaking out.

Digital Memory Books

Ugandans training for the “Memory Book” project, which teaches HIV-positive parents to communicate with their children about the difficult issues of HIV status, death, and estate planning. Families construct Memory Books to document family history.

The “Memory Book” project began with terminally-ill African immigrant parents in the United Kingdom who did not want their children to forget their personal and cultural heritage. Traditionally memory books are made with paper, photographs, and sometimes newspaper clippings. Creating a digital memory book allows family and friends to also include video, their favorite songs, family genealogies, digital photographs, and text.

A training program has spread the memory book project throughout Uganda, and partnerships have helped extend its use to other African countries, including Kenya, Zambia, Zimbabwe, Ethiopia, Tanzania and South Africa.

After creating a memory book one participant explained: “I am not worried about the future. The Memory Book and training have helped me explain to my children that I am positive and that one day I will die, so I have been able to prepare them. But I also explain that everyone dies one day, and I am just the same.”
Blogging is an empowering medium precisely because anyone can do it, though a supportive environment can be essential for confidence-building and skills-acquisition. Leadership flows from feelings of ownership.

**How can we link HIV-positive bloggers and people blogging on HIV/AIDS-related topics?**

Bloggers themselves, and institutions or organizations they are linked with, can make those networking connections. Organizations, institutions, and individuals who work with people who are affected or infected can create links within their own settings, and also engage in outreach to others. Rising Voices has developed a map — with details on HIV/AIDS-related blogs and bloggers across the globe — that will hopefully be one useful tool.

**How do we address fear of the unknown related to blogging for the first time?**

Starting off with a less-challenging topic and working up to addressing HIV/AIDS may be the best way to address a fear of the unknown. However, sometimes people will feel an urgency to address the topic, especially if it has an impact on their own lives. The regular practice of blogging, combined with a supportive environment and capacity-building activities, should lessen fear and replace it with self-confidence, or at least an openness to learning and developing new skills.

**How can we get people to blog on their own, as well as teach others?**

A balance of self-expression and peer education is important. Ask people to set aside time to blog on a regular basis, and help them to find outlets for their work. Encourage people to think of themselves as leaders, and help them understand how valuable and essential peer education is, both for the prevention of HIV/AIDS and for the general well-being of themselves, their families, and communities. Placing their own efforts within this larger context will hopefully inspire people to want to share, teach, and lead efforts to address HIV/AIDS, and other challenges to sustainable human development.

**Legal Issues**

A best practice for all bloggers is to not post anything online that you would not say in person. Though it is extraordinarily rare, bloggers can be sued for defamation and libel if they make false claims about a person or group which damages their reputation.
just for kiks

“I began reading more about the virus and the people who have it. I am one of those now and I should learn how to deal with it. Fighting an unknown enemy is surely a battle lost at the onset. I talked to friends of friends and we formed a group. We talked about a variety of issues and situations and experiences: diets, vitamins, those cocktails of pills and capsules they take everyday and which I dread to take soon, a healthy sex life, sex and responsibility, drugs and why we should never take them, reaching out to young people, reaching out to people who don’t have it, reaching out to people who don’t know anything about it. And yes, reaching out to people who don’t want to understand it.”

Location: Hong Kong
http://bikolanontsekwangbaklablog.blogspot.com/

Justin’s HIV Journal

As all of you know I’m very outspoken about who I am and about HIV Awareness, Prevention and Education. When I found out about my status I didn’t know what to do, but I knew I had to do something to get help and to help others. So I came up with Justin’s HIV Journal. My family was supportive but I only disclosed to the people that were old enough to understand the disease. I have two little brothers who I love dearly, named Brandon and Josh. They are younger than me, so I felt like I had to protect them or at least their image of me.

Once you become open about your HIV status it’s open to just about anyone, especially if you’re an outspoken HIV activist like me, who doesn’t mind sharing that about themselves. Brandon and Josh, I know you found out about my HIV through the Internet, I just wanted to tell you that I love you both and that it’s okay, I’m doing fine.”

Location: USA
http://justinshivjournal.blogspot.com

He is brave and optimistic about his situation. He still desires to love and to be loved.

Location: Taiwan

Autobiography of an HIV Positive

“While staying in Kathmandu, I heard about an NGO who provides care and teaches about HIV/AIDS. I joined and started taking many classes. It has shown me positive aspects of life. They told me that HIV/AIDS can’t be fully cured, but that there are drugs which can help to slow the decreasing rate of our immune systems and help us to live longer as healthy people. It’s distributed freely at the government hospital. We can live many years just as other non-infected people live. It makes me so happy. My husband and I started antiretroviral drug treatment there. Their teaching and programs give me a vibrant energy. It breaks many of the myths of HIV/AIDS that I had. It has given more happiness to my life, which I had lost many years ago. Then I began to think, why aren’t these types of programs available in our rural village, Achham, and I told myself that I will start one in my village.”

(Edited for clarity)

Location: Nepal
http://autobiography-of-an-hiv-positive.blogspot.com

Back in the Closet

“Back in June 2008, if I remember right, I got my first CD4 count when I was still with the San Lazaro Hospital. It was 343. By August, I was able to transfer to the RITM, where they took new baseline data. My CD4 had gone down to 328. Down 15 points in just 2 months. I attribute that to the stress and anxiety brought about by the ultimatum presented to me at San Lazaro; that I needed to tell someone in my family, before they started me on antiretrovirals. Something I just wasn’t prepared to do.”

Location: Philippines
http://backinthecloset.blogspot.com

有了愛滋~ 還能擁有愛嗎？

Description: For 3 years, Guan De has posted and shared his HIV-positive life with love stories on his blog.
It is important to never reveal anyone’s HIV status online unless you have been given permission to do so. A "Code of Conduct" for bloggers and blogging has been proposed, and is available at [http://www.is.gd/1CoWG](http://www.is.gd/1CoWG). Blogger.com has published guidelines for its blogs and bloggers ([blogger.com/content.g](http://blogger.com/content.g)) that balance freedom of expression with responsibility and respect towards others. Among the content they will not allow are various types of pornography; hateful and violent remarks; clear copyright infringements; private and confidential information; content that promotes dangerous or illegal activities; and content from anyone trying to impersonate someone else.


**Getting Started: Resources for New Bloggers**

There are literally hundreds of tutorials and guides that explain the basics of blogging and all aspects of digital media. Anytime you have a question you can go to [http://google.com](http://google.com), type in your question and click on the search button. You can almost always find an answer to your question. In this section we will link to a few guides that should help you get started.

**Choosing blogging software.** The first step is to choose a service to host your blog. Two of the most popular (and free!) blogging services are [http://wordpress.com](http://wordpress.com) and [http://blogger.com](http://blogger.com). Blogger is owned by Google and integrates nicely with other Google products. WordPress is based on open-source software and offers its users slightly more customization. Both services are great, and you can always switch from one to the other. Bloggers based in Africa might want to consider [http://maneno.org](http://maneno.org), which is aimed specifically at African bloggers in areas with slow Internet connections. It also has a focus on multilingualism and translation.

**WordPress Tutorials and Guides:**
- [http://en.flossmanuals.net/wordpress](http://en.flossmanuals.net/wordpress)
- [http://support.wordpress.com/](http://support.wordpress.com/)
- [http://lorelle.wordpress.com/wordpress-resources](http://lorelle.wordpress.com/wordpress-resources)

**Blogger Tutorials and Guides:**
- [http://www.blogger.com/tour_start.g](http://www.blogger.com/tour_start.g)
- [http://bloggerfordummies.blogspot.com/](http://bloggerfordummies.blogspot.com/)
- [http://is.gd/2oFem](http://is.gd/2oFem)

**Tips and Suggestions for New Bloggers:**
- [http://is.gd/2oFw4](http://is.gd/2oFw4)

If you read through some of the web pages linked to above, there is plenty of information to get you started. Eventually you might also want to start posting photographs, audio, and video content on your blog. See our “Introduction to Citizen Media” guide for an overview of online digital media. [http://rising.globalvoicesonline.org/guides](http://rising.globalvoicesonline.org/guides)

**Guides to Podcasting, Online Video, and Photography:**
- [http://www.podcastfreearmerica.com/](http://www.podcastfreearmerica.com/)
- [http://www.kcnn.org/mitv/](http://www.kcnn.org/mitv/)
- [http://tlc.ousd.k12.ca.us/~acody/digi1.html](http://tlc.ousd.k12.ca.us/~acody/digi1.html)

**Beyond Blogging: Other Useful Tools**

While this guide focuses on blogging to address HIV/AIDS, there are many other online tools to further advocacy campaigns, spread awareness, and build a network of peers. Networking sites like Facebook ([http://www.facebook.com](http://www.facebook.com)), MySpace ([http://www.myspace.com](http://www.myspace.com)), and Kabissa ([http://www.kabissa.org](http://www.kabissa.org)) allow individuals and organizations to create profiles and build a network of peers. Networking sites like Facebook...
Advice From a Veteran Blogger

Brian Finch is an HIV-positive Canadian blogger, social activist, humorist, and creator of “Acid Reflux,” dubbed “HIV’s First Blog Reality Show” http://acidrefluxweb.com

“The Internet facilitates technological activism. It gives control and voice to the individual, to express oneself in the way he or she deems fit. It is taking back power, creating a voice that is not defined by others. Personally, it is a way to define myself outside of the small box of HIV, to exist outside of the disease paradigm.

“The more people are writing openly about their status, the more other people will see that they too can take risks. An online, ‘open’ presence serves as a role model for others.

“There is no HIV/AIDS-related community history, let alone a history that is international. Most countries are very inward-looking. The Internet has helped to break that down. For example, a website can be seen by people around the world. For women in particular, in Africa and beyond, the Internet has been an amazing networking and support tool.

“Goals are very individualized. When one is beginning to be open about his or her status, the goals may be as much internal as external. One goal may be about improving coverage of HIV/AIDS, and encouraging general awareness. Another may be an act of empowerment, to challenge others or even your own community – however you define that – on notions of what it means to be HIV-positive. This is why I use humor in my own work and push boundaries.

“I find that many people like to write about how they got to where they are at that point and time. It’s hard to set a best practice, but I’d recommend starting to write what you would say in any conversation. An introduction and background come first. Then answer more questions: Why are you writing? What do you hope to get out of it? What is your history? What are the things we should know about you, to see you as a whole person, to feel a connection with you? Why should we want to come back and find out more?

“Humor is a way of reclaiming power ... I’ve seen HIV-negative individuals try to define and label us as many things. There is one thing we are definitely not supposed to be, and that is visible...having fun in life, while all the time being an activist by virtue of making oneself public. Humor has always gotten me through life, especially some of the toughest moments. When I found out I was HIV-positive, over twenty years ago, I didn’t know whether to cry or laugh. I chose to laugh as much as I possibly could. Dark humor became my best friend. I love it because it shocks, while giving me courage in the face of adversity. Humor was and continues to be a powerful weapon to confront the painful realities in our lives. It takes the awful and twists it around into an absurdity so exaggerated, it actually becomes funny.”


Join the Global Conversation

Now that you know the basics of blogging, it’s time to join the global conversation. Global Voices is a community of citizen media enthusiasts from around the world which aggregates, curates, and amplifies the international online conversation. Whether you’re looking for podcasts from Japan or captivating photos from Macedonia, Global Voices is an online village of everyday people sharing stories, photographs, and opinions from their corner of the world to yours. We hope that you take part in the conversation.

www.globalvoicesonline.org

Blogging Positively: Get Involved

There are many ways to become involved in the Blogging Positively community. If you would like to be included on our map of HIV-positive bloggers around the world please email Global Voices’ Public Health Editor Juhie Bhatia [http://globalvoicesonline.org/author/ juhie-bhatia/] with a link to your blog and the city you live in. We also encourage you to subscribe to the Blogging Positively mailing list [http://groups.google.com/group/rv-positively]

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Blogging for Healthier Policy in Ukraine

Pavel Kutsev, a leader in Ukraine’s harm reduction movement and co-founder of the non-profit organization Drop-in Center, uses his blog to fight stigma and to create awareness about the health needs of Ukrainians living with drug addiction and HIV/AIDS. Pavel defends the rights of drug users who participate in substitution therapy programs, which aim to discourage drug users from injecting street drugs with needles, thus mitigating the spread of the HIV/AIDS pandemic.

Kutsev, who is HIV-positive, knows first-hand the stigma and discrimination that face drug users and HIV-positive individuals. On his blog Pavel covers the various issues that are discussed in the Ukrainian community of injection drug users, including types of medication, health support services, and political activism to overturn recent decisions in some Ukrainian municipalities to ban substitution therapy. In addition, Kutsev posts his own autobiographical stories in order to share the lessons he has learned with his readers.

Kutsev says that blogging has helped him and his organization to be heard, and to become more influential. He has been invited to participate as an expert in working groups tasked with the development of the government’s substitution therapy policy, and believes that Ukraine’s Ministry of Health introduced its current policy of making some replacement therapy medications available at drug stores as a response to discussions in the Ukrainian blogosphere. Kutsev is working toward a global web-resource to unite the efforts of harm reduction activists that promote replacement therapy as a way to mitigate the spread of HIV/AIDS.

http://depo3p.livejournal.com/
http://rising.globalvoicesonline.org/projects/dropin-center/