Marissa Smith: ’To make an active change within the community, women living with HIV need to find their self-love.’

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LOVE POSITIVE WOMEN (LPW) is an ongoing project established by Visual AIDS artist member Jessica Whitbread in 2013. LPW is an international series of grassroots events that uses Valentines Day as a backdrop, creating a platform for individuals and communities to engage in public and private acts of love and caring for women living with HIV. Working from a place of strength, LPW focuses on the idea of interconnectedness, relationship building, loving oneself and loving ones community. Marissa Smith was one of LPW’s earliest collaborators, and in the interview below, she discusses her LOVE POSITIVE WOMEN Makeover Photoshoot, the particular experiences of women living with HIV, and the importance of self-care.

Visual AIDS: You met Jessica Whitbread in 2012 at the International AIDS Conference. What conversations did you have that inspired LOVE POSITIVE WOMEN and what were some of the motivations that initiated the project?
Marissa Smith: When I first met Jessica in 2012 I was on my own self-love journey and going through a rough time in life. In 2010 I started to get sick to my stomach all the time; I ended up losing my job and having to drop out of school. My confidence took a blow and on top of that I was having major issues with health coverage and trying to get the help I needed. The doctors could not figure out what was wrong and they suggested it might be mental. So I began my journey to heal my past traumas as I knew I had some major traumas that were holding me back in life.

As I started to peel back the layers of the “onion” of my traumas I realized I had lost my self-love and worth at a young age. I explained to Jessica that I learned in order to really do policy work and make an active change within the community women need to find their self-love first and build some confidence to know they can do this work, because without that foundation I don’t see us women moving mountains like we are capable. Policy work is hard and making active change within a community is hard but if we start within ourselves and build up ourselves we can make more happen. I just encourage self-love as a must in order to get woman to really make a difference. From there Jessica and I kept in touch and talks about LOVE POSITIVE WOMEN came up. I can’t remember exactly how it all got started. Jessica’s beautiful mind came up with most of the ideas. I may have just planted the seed of self-love.

You hosted a fantastic LOVE POSITIVE WOMEN makeover and photo shoot event in 2013 in San Diego. What was the idea behind the makeover and photo shoot?
The idea behind the makeover came from me loving to dress up. When I started to get sick all the time, when I was able to leave the house, I didn't want to look sick, and when I dressed up I felt a little better and at least getting complements that I looked good, even though I felt like crap, made me feel a little better. So I wanted to dress the women up and show them how good it feels to dress up every once in a while and that they are worthy of getting dressed up.

The photo shoot idea came from when I was first getting sick. I was not happy with my body. I lost lots of weight and I was still getting used to my new body. My cousin likes taking photos; she would use me as her model. I would just be me and she would capture beautiful pictures that really made me realize for the first time my true beauty. This made me feel good and helped me build my confidence. I wanted other women living with HIV to feel that similar feeling; I wanted them to realize how beautiful they truly are. I also got the idea for the women to take nude photos from one of India.Arie's songs, "Private Party." The lyrics stuck with me: "I'm gonna take off all my clothes / Look at myself in the mirror / We're gonna have a conversation / We're gonna heal the disconnection / I don't remember when it started / But this is where it's gonna end / My body is beautiful and sacred / And I'm gonna celebrate it." Those words gave me the idea about self-acceptance for the sign that the woman held in front of them during the photo shoot. I was able to give nine beautiful woman makeovers and personalized photo shoots, and then they all received four prints and extra photos on a disc. All of this was provided for free.

How did the photo shoots go, and what messages did you hope women would take away from the process?
The photo shoots went GREAT! The energy was intoxicating and full of joy. It was amazing to see the transformation of the women. Everyone worked together and showed sisterhood. I helped direct some of the photo shoots and encouraged the woman to let go and let their inner self out. I also encouraged the woman to take classy nude photos with a sign in front of them that was about self-acceptance. I wanted the woman to realize that they are beautiful inside and out, to learn to love themselves the way they are now, fully. I wanted to get the woman to live in the now. I wanted to gives these women sexy photos for the future so when they are in their '80s they can say, "Damn I was a hot mama! What was I complaining about!"

I wanted to help give the woman a start on or back on a path of self-love and I felt starting on the outside is the easiest and is a start somewhere. A few of the woman chose to do the nude photos and it was a great experience for all of them and all involved. One of the woman even decided she wanted to write a sign about how she disliked her body due to the HIV medication, which was powerful and also started a great conversation on dealing with our bodies on HIV medication; another part of learning to love ourselves. Overall it was a very great experience for all involved. I can't wait to do another one!

In what ways have you been involved in AIDS advocacy work? How do you feel organizations like Positive Women's Network (PWN) and the International Community of Women Living with HIV (ICW) have impacted the field of AIDS advocacy? And where do the gestures made during LOVE

POSITIVE WOMEN fit into these larger structures?
I have been involved in the HIV/AIDS community since I was 12; I started out as a public speaker living with HIV. Then I started to attend Ryan White Youth Conferences around age 12. I started to get involved in HIV Youth Council and got involved in trials in San Diego. I also did a few trainings on being a peer advocate and volunteered as an advocate around my community. I was part of a speaking tour at age 19. I got involved with the Positive Women's Network in 2011 and got to attend the International AIDS Conference in 2012, where I met Jessica and started to get involved with ICW.

I feel that organizations like PWN and ICW have impacted the field of HIV/AIDS Advocacy by giving woman living with HIV a stronger voice in the world. I feel they have helped give woman a voice about the true issues women living with HIV go through. They have helped educate other positive woman to make an active change and they educate negative people as well. I feel that Love Positive Woman fits into the larger structure because in order for woman to make a positive active change within their community they need to build up their foundation of self-love and self-confidence so that they can actually feel like they can do this! Doing activism and advocacy work is not easy, especially if you do not have proper self-care skills.

I have learned from my own personal experience and observing others that the main thing lacking was self-love and self-care, and those two are needed in the foundation to help make changes on a bigger scale. Self-love breaks down walls in our thinking and opens our minds, eyes and heart. With those open we can move towards a positive change in our world. Self-love is key in life, and many positive women I noticed had lost their self-love and they needed to gain it back or discover it for the first time if they have not ever experienced it. Self-love equals positive changes within our whole world, not just the HIV community.

What have you found to be particular stigmas that women living with HIV face?
The particular stigmas I have observed that woman face are the stigmas that they are to "blame" for the reason they have HIV; in other words, that they must have slept around or were into drugs so they are "dirty" in some way, when in fact that's not the case most times.

I also have observed the stigma that most women hold within themselves about HIV; they hold the stigma of what they learned back before they were diagnosed. They harbor that fear that they will die early or that no one will love them because they have HIV. In turn, a lot of them isolate themselves in their homes.

I have learned no one will love you until you love you. Also, the division of women by race adds more to the stigma around "who" gets HIV, considering HIV does not discriminate in any way. Any division within our own HIV community adds more stigma as a whole and more layers to the already complex issue of HIV stigmatization.

What were some of the highlights of your LOVE POSITIVE WOMEN event in the face of these difficulties?
The highlight of the makeover photo shoot was to see most of the woman come out of their shell!

They were completely themselves and did not hide. To see these women light up from the inside out because they were having fun with their peers and would not be judged whatsoever was awesome and pure magic. To actually see the women's transformation from the start to the end was seriously amazing. Most of the women came in quiet and shy, you could tell they didn't know fully what they had gotten themselves into. Everyone transformed once they had their hair and make-up done. We all got to experience sides of each other we have not experienced before and this made us closer.

One of my favorite highlights was when some of the women decided to take the nude photos. It really got some good conversations going and we all could relate on one level or another. To me it was also very powerful to see these normally shy women take some risks and do something they may have never thought they would do. We all laughed and cried about our struggles as woman living with HIV, and we all came from different walks of life, joined in unity and love for each other on this day. It was pure magic.

How can people who want to show their love for women living with HIV best go about doing so? How do you recommend other people interested in LOVE POSITIVE WOMEN get involved?
People that want to show their love for positive women can do so in any loving way they can think of! If you are a songwriter or love to play an instrument, you can write or play a beautiful song for a positive woman or women and happily post it on our Love Positive Women: Romance Starts at Home Facebook! You can ask a positive woman on a date or give a bubble bath gift basket, or do something creative that shows love! And of course share with all of us on our Facebook what you are doing for positive women!

I also encourage positive women to also show love for themselves! Take yourself on a date or give yourself that much deserved spa day or home spa day, or do anything that makes your heart and face smile! I recommend people to visit our Facebook page to show some love and feel free to ask us questions on how you can get involved. Showing love to positive women or in fact anyone can last all year long!

For more images from the photo shoot, visit Visual AIDS.

Marissa Smith's biography: I found out I was HIV positive when I was 8 years old, a year after my mom passed from an opportunistic infection from AIDS in 1994. At age 12 I began to help motivate my fellow youth that were prenatally infected to be active in their health and take their medications, and started to speak publicly around my community, telling my story about living with HIV. Soon after, I started to attend the Ryan White Conferences for youth and was doing workshops on self-empowerment. Back in San Diego I began to do some trainings to become a peer advocate to further myself so I could help my community more.

I have volunteered for the Mother, Child and Adolescent Program doing several things in the community, from speaking, to taking part in the HIV Youth Council and helping plan youth-centered events to spreading awareness about HIV/AIDS. When I was 19 I was a part of Who's

Positive Operation Get Tested speaking tour, we were able to put a human face to HIV and also bring free testing to the colleges we visited. I was able to learn some very valuable information on public speaking and the media. From there I also had the opportunity to speak for the NFL for their Rookie Symposium. At age 23 I found myself ill and having to prepare to transition into adult care which was also the start of the health care reform transition. I found myself unable to get the care that I needed and running into road block after road block to get the help I needed. I decided to be proactive and I joined the HIV Planning Prevention Group, which is the sub group of the HIV Health Services Planning Council in San Diego. I realized that being on the prevention group would help me get the services I needed.

I soon decided to join PWN as I realized that as an adult woman I would not be able to get the care I got as a youth because women are not properly counted by the CDC. I saw and was experiencing how women not being counted properly really affected our care and ultimately our health. Going to the International AIDS Conference in 2012 with PWN, I was able to get involved with ICW. Being a part of ICW North America I have helped start the initiative LOVE POSITIVE WOMEN: Romance Starts at Home, which is a way for each of us to express and show how we as women living with HIV are going to practice self-love, support and care as well as a platform for our allies to show us love around Valentine's Day. I am also helping develop ICW Chapter of Young Women, Adolescent and Girls. I have also done some work in the Mental Health Community to try to bring the HIV and Mental health services together, as most of HIV positive people suffer from dual diagnoses of HIV and Mental health.

I have volunteered my whole life; I do this work because I follow my gut and my heart. I have recently moved to South Lake Tahoe to focus on my own self love and care, as I have a life time of trauma and if I really want to help others and make that active change, then I must first help myself and work on things that have been holding me back from making my dreams fully happen. I hope one day to start my own non-profit and continue to be a part of good changes in the HIV community or the global community as a whole.

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