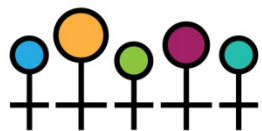


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# Using Social Media as a Tool for Empowerment and Advocacy

*National Women and Girls HIV/AIDS  
Awareness Day*

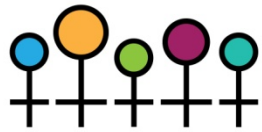
**2015**



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# Webinar details

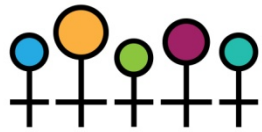
- Webinar will last approximately 90 minutes
- The first 60 minutes will be a moderated; followed by Q & A with speakers/participants
- Please use the live chat box on the left side to enter questions while someone is talking; questions will be put in a queue
- Participants will be in “mute” mode until the Q&A
- We ask that all participants keep their line on “mute” unless asking a question or in a discussion during the Q&A
  - To unmute yourself (if using your telephone), press \*6, or click on microphone icon at the top of your screen (if using computer microphone)
  - To mute, use your phone “mute” button
- Please take brief survey at end of webinar!



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# About The Well Project

- The Well Project is a non-profit organization whose mission is to change the course of the HIV/AIDS pandemic through a unique and comprehensive focus on women and girls
- Founded by Dawn Averitt, who was diagnosed with HIV in 1988 at age 19 and is one of the nation's most prominent HIV treatment advocates
- Since 2002, The Well Project has focused on three critical gaps related to women and HIV: information access/health literacy, community support/advocacy and targeted research
- Access our resources at [www.thewellproject.org](http://www.thewellproject.org)
- Please take our survey, closing on March 13!  
<http://www.thewellproject.org/your-voice-counts-well-project-survey>

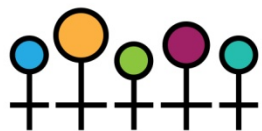


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# About NWGHAAD



- NWGHAAD is an annual, nationwide observance that sheds light on the impact of HIV/AIDS on women and girls
- Takes place every March 10, and this year is the 10th observance of NWGHAAD!
- NWGHAAD is an opportunity to recognize the impact of HIV/AIDS on women and to raise awareness!
- Tag #NWGHAAD on social media today! Let's make #NWGHAAD a trending topic!
- For more information, go to: <http://www.womenshealth.gov/NWGHAAD/>



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# Webinar agenda



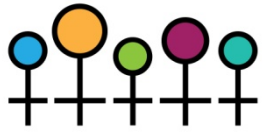
Sharing your story to break down the impact of HIV-related stigma, **Michelle Anderson**, Community Advisory Board, *A Girl Like Me* blogger



Maximizing the impact of your message by avoiding stigmatizing language, **Vickie Lynn**, Community Advisory Board, *A Girl Like Me* blogger



How to best use and navigate major social media tools, **Maria Mejia**, The Well Project Global Ambassador, Community Advisory Board, *A Girl Like Me* blogger

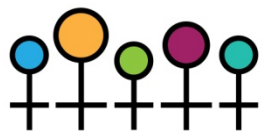


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**The power of sharing your  
story to fight stigma**

***Michelle Anderson***

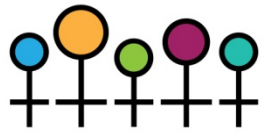




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# My personal timeline

- May 17, 1970 – I was the first child born of a twin birth
- Age 4- Birth of my youngest sister (**Disconnection from Father**)
- Age 5- First time I was molested (Germany)
- Age 6- A psychologist suggests to my parents to lock me in a room with nothing but a potty chair with only bread and water to cure me from bad behavior (**Severe emotional trauma**)
- Age 7-10- Molestation would continue by family members and friends of family
- Found out father wasn't real father while entering a court room to be adopted by him. (**Severe emotional trauma**)
- Developed low self esteem due to being an overweight child and feelings of being unloved.
- Age 12-14- Began to become promiscuous. Started experimenting with sex (**Sex was never talked about in my family**)
- Age 15- I became pregnant by 24 year old man
- Age 16- Dropped out of school to care for my child; First time experiencing homelessness

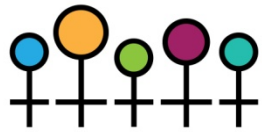


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# My personal timeline

- Age 17- My first abusive relationship (Severe emotional trauma)
- Age 18- Second pregnancy ending in miscarriage brought on by physical abuse
- Older sibling and confidant was murdered. (Severe emotional trauma)
- Age -19-20 Experimenting with alcohol and marijuana
- Age 21- Third pregnancy; Married while pregnant with 3<sup>rd</sup> child
- Age 23-24 Split from husband due to his affair (Severe emotional trauma)
- Moved back to Texas. One night stand. Fourth pregnancy
- Tried crack-cocaine
- Age 24- 26 Abused drugs
- Lost custody of children (Severe emotional trauma)
- Homelessness
- Age 26- Gang raped
- Age 27-28- In and out of jail
- Age 28- Entered rehab. Took HIV Test.





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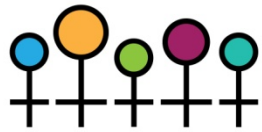
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Diagnosed with HIV

April 11, 1999

Age

28



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# Sharing my story

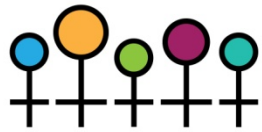
- When do you share your story?

Disclosing your status can be a very difficult. However, finding a safe place to share your story will empower you to continue to strengthen your resolve.

- Take baby steps. Share your story with friends, family or in small settings that are safe.
- Utilize your story to raise awareness and educate communities.

**Sharing stories takes the burden of shame away.**

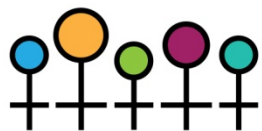
- The impact of sharing can:
  - Helped others feel they were not alone
  - Decrease stigma
  - Empowered others



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# Sharing my story through blogging

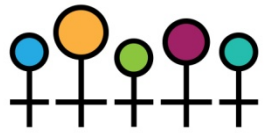
- Blogging can be used to:
  - Share every day experiences living with HIV.
  - Allows one the ability to “unpack baggage”
  - People can also blog anonymously if not yet public with status, which can still be a very empowering and helpful step
  - Many AGLM bloggers are anonymous, and some begin their HIV advocacy that way
- Impact on you
  - Healing
- Impact on readers
  - Healing, feeling less alone, decrease stigma
- Tool for HIV advocacy
  - Call to action
  - Raise awareness on topics (criminalization, Cicely Bolden)



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# Since becoming an advocate: my personal timeline

- Obtained G.E.D.
- Attained affordable housing
- Enrolled in college (Social Work)
- Reunited with children
- Disclosed my status
- Lead Peer Educator/Programs Assistant for The Afiya Center
- Public Speaker
- Co-Chair for the Campaign to END AIDS Texas Southwest
- Board member for ADAP Advocacy Association and AIDS Services of Dallas
- Activist/Advocate regarding HIV/AIDS and its impact on African American women and female adolescents
- Third runner-up (x2) Ms. Texas Plus America Pageant

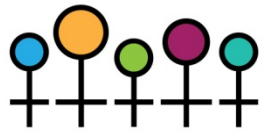


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# Since becoming an advocate: my personal timeline



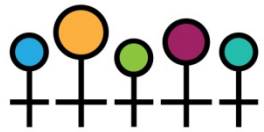
Made history by becoming the first OPENLY HIV positive woman to ever run for and win a national pageant title of 2011 Ms. Plus America



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# Since becoming an advocate: my personal timeline

- CEO/Founder of Metamorphic Designs
- Treasurer for ADAP Advocacy Association
- Motivational Speaker
- *A Girl Like Me* Blogger
- The Well Project Community Advisory Board
- NWGHAAD Ambassador
- Member of PWN-USA



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# Thank you!

**For your continued support in allowing me to foster meaningful changes in the lives of others!**

**The Well Project**

***AGLM* Bloggers**

**Common Threads**

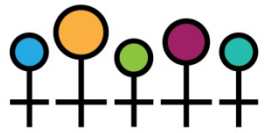
**The Afiya Center**

**Positive Women's Network - USA**

**ADAP Advocacy Association**

**ACT Against AIDS**

**Greater Than AIDS**



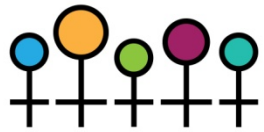
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# The Well Project

## Use of Language in HIV Advocacy

*Vickie Lynn*



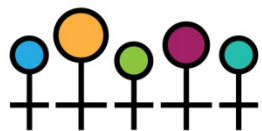


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# Reporting on HIV and AIDS

- “Because reporting on HIV and AIDS ultimately deals with matters of life and death, and because many people will form their understanding of HIV and AIDS through the media, the story must be approached with clarity, precision, and sensitivity.”

Kaiser Family Foundation. Reporting  
Manual on HIV/AIDS

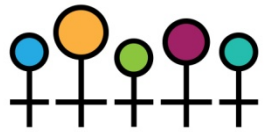


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# Language

- Focusing on use of language may be the first place to start in order to address stigma, social exclusion, and discrimination against people living with HIV
- Language
  - Helps to shape our world
  - Describes and gives meaning to our lives
  - Persuades and changes minds
  - Can destroy or empower

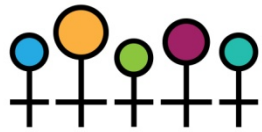




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# Language in HIV Communication

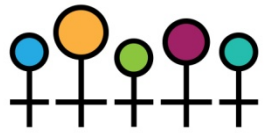
- Stigma
  - The public component (reaction of general public to people living with HIV)
  - Personal or self-stigma (prejudice that people with HIV tend to turn towards themselves)



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# Stigma

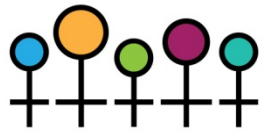
- Labeling and stereotyping people
- Creating a division – “us” and “them”
- Discriminating against people based on the created label



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# Stigma

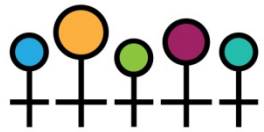
- Stigma works its way into policy decisions, access to care, health insurance, employment discrimination, and in research funding and priorities.



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## Next steps

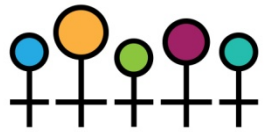
- What can we do to address stigma issues in our communities and why does the use of language matter?



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# Not appropriate language

- Full-blown AIDS – do not use
- Referring to AIDS as a virus – it is a diagnosis and cannot be transmitted from one person to the next
- HIV virus – is redundant; HIV stands for Human Immunodeficiency Virus
- Victim, Sufferer, Contaminated – do not use

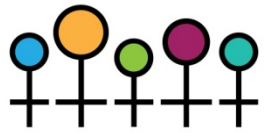


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## Examples of referring to people as illness or disease

- My brother is cancer
- Her mom is HIV+
- That man is depression

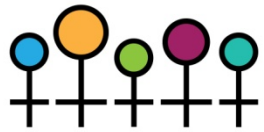




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# People first language

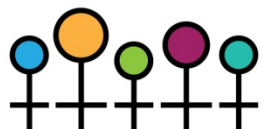
- Rather than using labels to define individuals with a health issue, it is more appropriate to use terminology that describes individuals as being diagnosed with an illness or disorder



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# Language

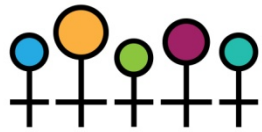
- We want to use language that is precise, accurate, and objective in order to remove value judgments



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# Preferred language

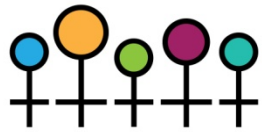
Stigmatizing	Preferred
HIV patient, AIDS patient	Person living with HIV
Positives or HIVers	
AIDS or HIV carrier	
HIV-infected mother	Mother living with HIV
Died of AIDS, to die of AIDS	Died of AIDS-related illness, AIDS-related complications or end-stage HIV
Fight against HIV and AIDS	Response to HIV and AIDS or HIV and AIDS response



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## Next steps

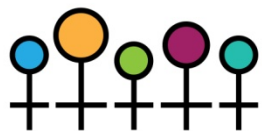
- Avoid labeling and stereotyping people living with HIV on the basis of media and societal stereotypes
- Learn more about HIV stigma and discrimination
- Speak up about HIV stigma
- Listen to people who have experienced HIV stigma and discrimination



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## Next steps

- Watch your language – talk about people first, then their illness
- Provide support for organizations that fight HIV-related stigma
- Use appropriate language, medically correct language
- Portray people with HIV living positively



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# Stigmatizing media coverage

- Write editorials, letters to the editor or author of the story or blog, and submit on-line comments

## Signs of Full-Blown AIDS

Last Updated: Jan 28, 2015 | By Virginia Franco

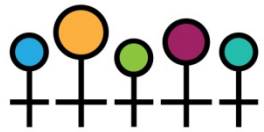


Extreme weight loss is a classic symptom of full-blown AIDS. Photo Credit scale image by PinkShot from Fotolia.com

Without HIV treatment, full-blown AIDS usually takes about a decade to develop. During this last phase of the disease, the virus severely damages the immune system to a point where the body can no longer fight a number of viral, fungal, bacterial and parasitic infections that invade. Any one of these infections is life threatening, and most people with AIDS eventually succumb to them.

### Night Sweats

While night sweats can also begin prior to developing full-blown AIDS, they also occur during this end stage.

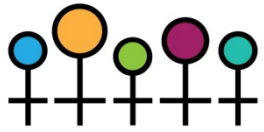


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If we spoke a different language,  
we would perceive a somewhat  
different world.

-Ludwig Wittgenstein

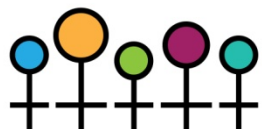


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# How to best use and navigate major social media tools

*Maria Mejia*





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# Creating a “brand”

- Importance of “creating your name”

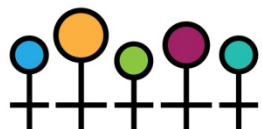
*If you want to be very public and create a following, consider creating a catchy name that brings attention to your cause! I created Maria (HIV) Mejia on purpose to bring attention to my cause and mission and attract others living with HIV and those in search of information.*

- Using your name in activism and advocacy

*Having a name brand can help you get your message across, and can bring traffic to your agency and cause! It will make you well known so you can reach all areas you want to be seen in. It can also get you work! The more visible and relentless you are with social media, the better! If I did it, anyone can! When you Google my name, I am in the first 20 to 30 pages!*

- You can also participate anonymously

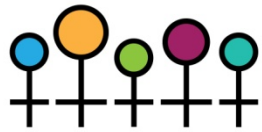
*If you are interested in joining online communities around HIV, but are not open about your status, you can also create a nickname or fake name that will allow you to remain anonymous.*



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# Finding others living with HIV

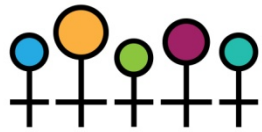
- There are many online communities on Facebook, YouTube and Twitter!
- You can find people and groups by searching for information with hashtags
  - Hashtags are when you put a “#” before a word, phrase or name. For example, on Twitter, Facebook, and Instagram, you can search “#HIV” and it will bring up all posts that include that hashtag in it
  - Common hashtags for HIV advocacy include #HIV, #AIDS, #VIH, #SIDA, #ACTIVISM, #STIGMA
- Look for online communities like The Well Project!
  - This is a place where women and girls from all over the globe connect with each other, exchange information and experiences



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# Social media tools

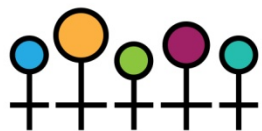
- Using social media tools in advocacy is easier than it looks!
  - Facebook has groups, personal pages, public or private organizations, everyone is there!
    - This is where I started
  - Twitter uses small messages, and can reach a lot of people
    - Use hashtags and tag others (which I will show you soon how to do) that are a part of our mission
  - YouTube videos are great for visual activism
  - Instagram is a place to post pics of your journey or cause!
    - I utilize this because this is where the youth is!
    - Hashtagging there is very important



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# Facebook

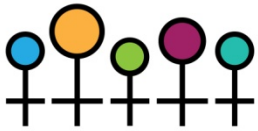
- Facebook is a very powerful tool and where you will always find me!
- You can have a personal profile page, create a group (public or private) or a page for your organization or brand
  - I founded two of the largest online support groups for people living with HIV and affected by it; we now have almost 40,000 members
- Identify others who are communicating about the topics you're interested in
- If you create a nickname or false name for your page, you may not find as many "friends" right away as people won't know you, but can let you post in groups with no worrying around disclosing status



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# Facebook step-by-step

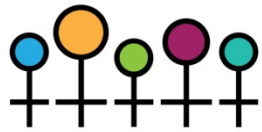
- Status updates; liking and commenting
- Sharing links: copy and paste the URLs articles into status
- Uploading photos
- Tagging individuals and pages
  - Use @ to tag people and pages
  - Always make sure you've checked with someone before tagging them in a status update or photo, especially when related to HIV
- Sharing other people or page's status/links
- Hashtags, use # to hashtag based on topic or trending news
- Creating a group or a Facebook page
  - Need to have a profile page first



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# Twitter

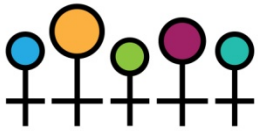
- Twitter is a place that everyone uses!
- The more people you follow, the more people will follow you
- To get followers, you need to be active on Twitter, posting tweets, retweeting others, adding “favorites”
- Moves fast, so it is good to post often, 2-10 times per day!
- Good for small messages (no more than 140 characters)
- Great for sharing links to articles, news and uploading photos or videos
- A good resource for searching for the latest information on a topic (use hashtags for searching)
- Example of a tweet for #NWGHAAD:
  - Help reduce stigma by donating a tweet for the Nat'l Women & Girls HIV/AIDS Awareness Day:  
<http://bit.ly/1DUsmxV> #NWGHAAD @thewellproject



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# Twitter step-by-step

- Creating a Tweet
- Retweeting others
- Tagging others that you want to see the message or are part of the message
- Using hashtags in your posts such as #HIV, #Stigma
- Search using hashtags (#NWGHAAD, #HIVwomen)
- Favoriting posts
- Uploading a photo (this takes up characters)
- Pasting a link (this takes up characters)
- Finding people to follow

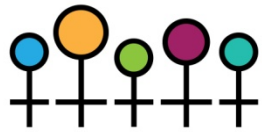


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# YouTube

- YouTube is where I started my bilingual vlogs (video blogs). I have now 700,000 viewers and growing!
  - People are very visual and they like to see the person behind the message
  - You can find other vloggers (video bloggers) talking about HIV just by searching it
- It is very simple to upload vlog. You'll need a smart phone or laptop with a camera, and a good connection to the internet.
- To find my YouTube, Google "Maria HIV Mejia" or in YouTube just type "HIV videos" or "Maria Mejia"
  - <https://www.youtube.com/channel/UC5rLo708TPsjkyj0ll4loKQ>
- Consider naming your site something simple; use your name, organization and/or something that references HIV/AIDS

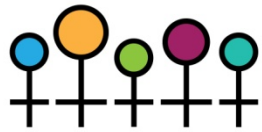




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# YouTube step-by-step

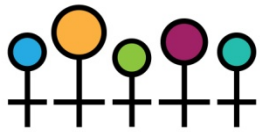
- Creating an account vs. creating a channel
  - Channel allows you to post all your videos in one place, and people can subscribe
- Uploading a video
- Adding a description and links, hashtags
- Sharing a video
- Monitoring comments
- Finding and following others



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# Instagram

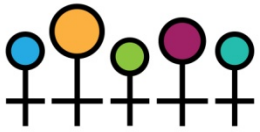
- Instagram is a place where we post pictures
  - Many people don't understand the benefit of pictures
  - People are very visual just like in videos!
- Post a picture and hashtag away!
  - This also brings traffic and attention to your cause!
- I make sure that my status briefly explains who I am
- Post a link of your website, agency or anything you want to bring attention to or whatever is trending



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# Bringing it all together

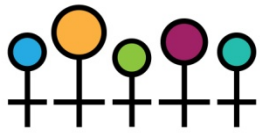
- You can use all of these tools in an interconnected way to increase traffic for your cause, name, or site
- Once you have created your brand, it is good to create accounts and reserve it on each social media platform, even if you don't use it right away
  - For example, Facebook.com/**YourName**; Twitter.com/**YourName**; YouTube.com/**YourName**; Instagram account: **YourName**
- YouTube, Facebook, Instagram and Twitter have settings that help you connect all your social media
  - For example, if I upload a video to YouTube it sends it off to Facebook and Twitter and Instagram!
  - It is easier than you think
  - You just have to look around and get to know the tools you have! and if you do not know...ask :)



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# In conclusion

- Please do not be afraid to utilize social media! It can be a great way to get your messages out to others and build community.
- If you don't know something, I would be more than happy to explain!
- In emails and communications, always include contact information, including Facebook pages, Twitter handle, IG, email, phone number, etc (everything you feel comfortable including)



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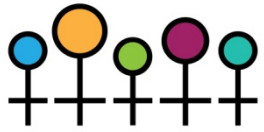
# Links to Resources

## **The Well Project**

- Website and A Girl Like Me: [www.thewellproject.org](http://www.thewellproject.org)
- Facebook: [www.thewellproject.org/facebook](http://www.thewellproject.org/facebook)
- Twitter: [www.twitter.com/thewellproject](http://www.twitter.com/thewellproject)

## **Maria Mejia, Global Ambassador for The Well Project**

- Email: [mmejia@thewellproject.org](mailto:mmejia@thewellproject.org) and [mariahiv1111@yahoo.com](mailto:mariahiv1111@yahoo.com)
- YouTube: <https://www.youtube.com/channel/UC5rLo708TPsjkyj0ll4loKQ>
- Facebook: <https://www.facebook.com/mariahivmejia>
- Twitter : <https://twitter.com/MariaHivMejia>
- The Well Project: <http://www.thewellproject.org/users/mariatmejia>
- Facebook Group English: <https://www.facebook.com/groups/mariahiv/>
- Facebook group: Spanish <https://www.facebook.com/groups/mariahiv1111/>



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**THANK YOU!!!**

*Please take brief survey upon close of webinar!*