

## 2016 Activities Summary

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January 1, 2016 - March 31, 2016

### Quick Description (Quarter-at-a-Glance)

- Awareness video “Understanding the Importance of Women and Minorities Participating in ACTG Network Clinical Trials.”

### Roles & Development of Praxis

- ★ **Presenter** on video and board member advocating for **wider participation**, including more women and people of color, in **medical studies for HIV**.
- ★ **Loved-one and parent** of HIV affected individuals **advocating** for wider participation of **marginalized populations in medical studies**.
- ★ **Collaborating** with **several advocacy groups** including: The Women's Outreach Workers (WOW) Project, Susan E. Cohn, MD, MPH, Investigator at our Northwestern University Site, Women's Health Inter-Network Scientific Committee (WHISC) and the Underrepresented Populations Committee (UPC)

### Values-at-Work

- Spreading awareness for the need of inclusion of marginalized populations (including, but not limited to, people of color) in medical studies for new HIV drugs, both within the HIV community and society at large.
- Targeting the intersections of marginalized communities within a larger cause (including intersections of children, gender, and people of color), to advocate and voice their unique needs, which are often overlooked.
- Teamwork with different groups and people, often with differing goals and visions, to make knowledge and awareness widely available.

### Events Timeline

- Advocating for Diversity in Clinical Trials--“Understanding the Importance of Women and Minorities Participating in ACTG Network Clinical Trials” online video (Advancing Clinical Therapeutics Globally)
  - ◆ March 1

### Lunches of Love

- Ongoing project from 2016 - 2019 twice annually
- K-12 and college student volunteers.



Lunches of Love

- Collaboration with Texas State Technical College (TSTC) and Advocacy Without Borders.
- Lunches of Love (LOL) committed to helping end childhood hunger in Fort Bend County by providing a free nutritious sack lunch during extended school holidays and weekends."
- Lunch bag decorating sessions and food donation drives.
- Feeds thousands of impoverished children at over 20 public schools and satellite locations.

### **Featured Activities**

In an ongoing effort to protect Part D in the Ryan White program, a federal program that finances local HIV & AIDS healthcare and programs, Dr. Onaiwu posted the following blog post on March 24 2016.

*As I have shared in previous posts such as this one, the President's new fiscal year budget (which begins October 1st) for the second year in a row has proposed to eliminate Ryan White Part D, consolidating it with Ryan White C. Ryan White Part D funds care and services for women, infants, children, and youth, (teens, young adults) while Ryan White Part C funds services for early intervention and capacity development.*

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*Ryan White is a "payer of last resort" which means that to qualify for it you have to meet certain income requirements and also need to be uninsured or underinsured. So Part D is serving individuals who are already experiencing economic hardship. Add to that the fact that youth and women in general - HIV positive ones in particular - are likely to face challenges such as unemployment, co-morbidities, virologic failure, abuse, substance use, and housing instability...and you can see that we are dealing with a population that is extremely vulnerable.*

**Advocacy Without Borders**

-Contact information must be provided: Name, physical address, and telephone. If you do NOT wish to be contacted, please do not provide this information. If you do provide this information, we can use the name, address, and phone number of the Ryan White Part D Initiative, which is below:

Name: Save Ryan White Part D Initiative

Address: in c/o The HIV Resource Group; 500 Lovett Blvd, Suite 100; Houston, TX 77006

Phone: [\(713\) 526-1016](tel:7135261016)

*Today, I'm asking you to stand with us. Many of us are advocating for Ryan White Part D - JOIN us. There are many ways you can help, but the most pressing one is to help speak up for Part D with our legislators.*

**We need you to help make contact about Ryan White Part D; the Senate Appropriations Office is accepting written and email testimony about the proposed budget until close of business April 3, 2015.**

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Source:

<https://advocacywithoutborders.blogspot.com/2015/03/send-email-or-letter-by-april-3rd-to.html>

## **April 1, 2016 - June 30, 2016**

→ Two White House Panels

### **Quick Description (Quarter-at-a-Glance)**

- National Transgender HIV Testing Day.
- White House Inaugural Forum On Civil Rights of Parents with Disabilities as Presenter.
- ACTG (Advancing Clinical Therapeutics Globally)/ACTG Network – AIDS Clinical Trials Group event in Washington, DC.
- White House Forum on LGBT and Disability Issues.

### **Roles & Development of Praxis**

- ★ **Leadership position in promoting** and presenting for HIV testing for Houston's **transgender** population in recognition of National Transgender **HIV Testing Day**.
- ★ **Two** instances of participating in **White House forums**, including as a panelist, concerning **disability & civil rights**, advancing conversations and concerns for marginalized **disabled** communities, and their intersectionality, including **parents & children** and **LGBT+** communities.
- ★ Ongoing commitment to **advocating diversity in medical trials**, particularly for HIV and AIDS medications, with Advancing Clinical Therapeutics Globally group.

### **Values-at-Work**

- Promoting awareness as to the importance of HIV testing for marginalized communities to ensure their safety, awareness, and representation.
- Advocating for diverse populations within the disability community on a national level, working directly with lawmakers and advisors within the White House.
- Championing civil rights for disabled communities, particularly for parents (as a parent) to assisting disabled children.
- Representing and speaking for marginalized groups within the disabled and LGBTQ+ community, addressing the intersectionality of both communities.
- Working on access and representation in medical trials for HIV pharmaceuticals.

### **Events Timeline**

- First National Transgender HIV Testing Day--Presenter & Co-host in Houston, TX
  - ◆ April 18
- Civil Rights Forum--White House Inaugural Forum On Civil Rights of Parents with Disabilities/Forum on the Civil Rights of Parents with Disabilities--Panelist
  - ◆ May 5
- National Gathering--ACTG (Advancing Clinical Therapeutics Globally) Network – AIDS Clinical Trials Group event in Washington, DC.
  - ◆ June 1
- Disabilities Issues Forum--/White House Forum on LGBT and Disability Issues/GCAB Representative in Washington, DC
  - ◆ June 27



## **Featured Events**

Attending a White House forum or panel is certainly a notable event, and this quarter included two! For the first presentation, Dr. Onaiwu didn't have their speech or notecards because they had to evacuate their hotel due to a bomb threat! Read their brief description describing this event below In Their Words.

It's easy to overlook the credentials of Dr. Onaiwu while focusing on the ecosystem of their body of work in the advocacy and activist sphere. Dr. Onaiwu has held innumerable advisory, executive, and board positions throughout their career, many not spelled out in this document for the sake of brevity. This information is (currently) available on Dr. Onaiwu's LinkedIn profile. However, in the case of attending the White House, it seems relevant to list some of the board credentials relevant to the invitation.

- Co-Chair Global Community Advisory Board of the ACTG (2010-2019)
  - Network Community Site Representative
  - Decision-maker and Spokesperson for international group, comprising approximately 60 Community Advisory Boards around the world.
  - This overlaps with decades of work with ACTG, which preceded and overlaps with this document.

As Co-Chair, Dr. Onaiwu had a thorough understanding of clinical research processes and acted as a liaison between the research community and those the research was about. During their time with the ACTG, they relentlessly advocated for marginalized people (women, people of color, the LGBTQ+ community) and HIV medical research. This included advocating to preserve Part D of the Ryan White program, among countless other campaigns and efforts. During this time, Dr. Onaiwu's concern naturally extended to healthcare issues for families (as they, too, are passionate about parenthood), pregnancy, maternal and infant health care issues, and intersections with other margins, like race and LGBTQ+ concerns.

- Board Member, Lurie Institute for Disability Policy (2016-present). The Lurie Institute of Brandeis University funded by the National Institute of Disability, Independent Living, and Rehabilitation Research helps families with disabilities by providing training and information, related to current research. Roles include:
  - National Center for Disability and Pregnancy Research.
  - National Research Center for Parents with Disabilities.

- Vice Chair Executive Board of Directors, Autistic Self Advocacy Network (ASAN) (2016-2020). ASAN provides advocacy and information about autism, disability rights, systems change through several different advocacy projects.
- Various Intersectional Advocacy and Education Endeavours
  - Through years of work advocating for the HIV community, including working to end the stigma of HIV, creating a positive community for people with HIV and their loved ones, championing inclusion and diversity in HIV research and accessibility to trials for new drugs, Dr. Onaiwu's passion for advocating branched out to include issues of race, gender, neurodiversity, disability, and the LGBTQ+ community, all of which affect them or their loved ones directly.
  - As an educator with an M.A. in Special Education, specializing in Developmental Disability, they have both an understanding of pedagogy and real life teaching experience.

### **In Their Words**

They briefly describe the experience of presenting in front of the White House, including not having their speech or notes for their presentation because of a bomb threat.

*...As one key example, some years ago I served as an expert panelist at the White House Inaugural Forum on Civil Rights of Parents with Disabilities. Although I didn't have my speech nor my notes present as a result of having to hurriedly evacuate the hotel in the wee hours because of a bomb threat, I gave a talk identifying and addressing common barriers families encounter as they attempt to navigate the complexities of various systems (i.e., disability services, schools, medical care, etc.) for themselves and/or their children. Although the forum was by invitation only, the content was shared in part on the White House official media broadcast, YouTube channel and website.*

*I returned to the White House a second time when I was invited to the White House Forum on the LGBT and Disability Issues, held on National HIV/AIDS Testing Day. Along with my colleague Angel Hernandez, a queer disabled Puerto Rican activist, I officially represented the Global Community Advisory Board of multinational AIDS Clinical Trials Group. The Forum highlighted various community led efforts focused on LGBTQIAP+ people with disabilities and hosted a moderated discussion on best practices to promote inclusion.*

Source: Dr. Onaiwu's doctorate thesis. *Bringing Fire to the People: Activist Scholarship, Creative Collaboration, & International Advocacy Through The Lens of Black Disability Studies.*

**July 1, 2016 - September 30, 2016**

### **Quick Description (Quarter-at-a-Glance)**

- HAART Standard Version of the PROMISE Study: Promoting Maternal and Infant Survival Everywhere.



### **Roles & Development of Praxis**

- ★ For years, Dr. Onaiwu had been involved in **HIV** and **AIDS medical research**. This particular study (HAART) was to investigate the impact of highly active antiretroviral therapy taken during **pregnancy**.

1077HS is a randomized strategy trial, which is part of the PROMISE studies (1077BF, 1077FF, P1084s, and 1077HS). 1077HS is conducted among women who receive highly active antiretroviral therapy (HAART) during pregnancy for purposes of prevention of mother-to-child

- ★ Taking on the role of **Community Forum Presenter and Co-Host**, this event focused on **promoting maternal health** for all, regardless of minority or marginalized status. As someone others look to for awareness and guidance of social awareness, **maternal/pregnancy health** is often overlooked for **people of color** and members of the **LGTBQ+** community. Thus, promoting maternal and infant survival is a large part of Dr. Onaiwu's advocacy praxis.

### **Values-at-Work**

- Highlighting issues and concerns directly impacting the lives (as in matters of actual life-and-death) and well-being of minorities and people in the LGTBQ+ community and their children.
- Involved in HIV medical research, especially as it overlaps concerns about diversity, representation, gender identity, and health for babies and pregnant parents.

### **Events Timeline**

- Maternal Wellness Study--IMPAACT Network/HAART Standard Version of the PROMISE Study: Promoting Maternal and Infant Survival Everywhere--Community Forum Presenter, Co-Host in Houston, TX
  - ◆ August 1

## In Their Words

Passion is an intangible that can be hard to capture in the work people do. This blog post is brimming with Dr. Onaiwu's passion for the work they do. (Note: it is from a different date than what is covered in this timeframe, but the sentiments are relevant.)

*Like most activists, I do what I do because I love it. It's a core part of who I am. It isn't for accolades, it isn't for attention, it isn't for financial or personal gain, it isn't for fame. Although it is rewarding, it is also very much a sacrifice; often demanding time, effort, money, and emotional/cognitive/physical energy - all things that for many of us are in short supply. And a great deal of the time, we will hear many more "No" answers than "Yes." Yet we do - and will - keep going.*

*We will encounter more opposition than we will support; will face more rejection than inclusion; will plant seeds that we know we will never reap in hopes others after us will benefit from our work; will expend money, time, and "spoons" knowing that even more will be required and that we will have to replenish them on our own while still finding a way to give.*

*And yet we don't stop, and won't. This is who we are. This is who I am.*

*I don't need pay. I don't need a pat on the back. I don't need to be well-known. I don't need kudos, media coverage, or recognition. I don't need thanks. I don't need friendships. I'm not opposed to nor will I refuse any of these things should they happen to be given to me along my journey - indeed I have made some strong friendships that I treasure through the years and have found that attention can assist the cause. And as someone who's far from wealthy, money helps advance what one is able to do as well, as it provides a mechanism to reach more people and to help others. I don't see any of those things as "bad" things. They're just not a need. I can, have, and will continue without any of them - without being given a dime for my travel or my contribution, without being featured in any story or show, without a "following" of any type. Like most of us, while those can be helpful "extras" if available, that isn't what I'm here for, and I don't "need" any of that.*

*But what I do need is this.*

*Don't effin' sabotage me and mine. By "mine" I mean my brothers and sisters in the struggle. Don't set us up. Don't appear to be an ally and then stab us in the back. Don't make promises and then renege on them. Don't play "devil's advocate." Don't play games with what we're doing - we're fighting for our, and other people's lives here.*

*Don't hurt us and don't play us. If you're not going to be "for" us, I can understand. Just please don't stand in the way.*

*I'm going to be all right. My family is too. I am an advocate through and through and that will never cease, but my initial responsibility is to my family. They are my top priority - first, last, and always. I will always seek to make certain that no matter the social, political, or economic climate and/or no matter my struggles and shortcomings, I will provide for their needs in order to ensure to the best of my abilities that they have happy, healthy, fulfilling lives.*

*But it's not about me and my family. I don't do any of this out of need. I do it because there's a world of people out there like me. There's a world of people out there like my daughters. There's a world of people out there like my sons. And like one of my idols, Dr. Martin Luther King Jr. once said, "Until all of us are free, none of us are free."*

*It's not good enough that MY family has access to HAART and PrEP. It's not good enough that MY family receives an inclusive education. It's not good enough that MY family lives stigma free, that we are a proud HIV affected, Autistic, adoptive, neurodiverse multicultural family, that we do not hide from nor feel limited in any way by who we've been made by God to be. These victories weren't given to us; we fought for them. But the fighting doesn't end just because we've had some successes in my little circle of the world.*

*As long as even one person is unable to have similar access, similar acceptance, similar resources, similar options, how can I be content? How can I rest? I can't.*

*But when I have to contend with soul-crushers and those who sabotage those of us who've put ourselves out there by choice as advocates, it takes away from my ability to effectively "do" for others. It robs me of valuable time and energy that could have been better utilized in others ways to help others. It drains me and makes me less capable. It makes me less willing. It makes me tired and makes me less focused and less able to summon what I need to give my all to fight for others who need me.*

*And believe me, people need me. Not because I'm anything special - I'm just Morénike. I'm ordinary. But ALL hands on deck are needed. The Bible states, "The work is plenty, but the workers are few." Every last one of us that is helping in our own individual and collective ways is needed out here. We cannot afford to lose ANY one of us.*

*We need the self-advocates, we need family advocates, we need allies, we need caring professionals, we need concerned family and community members, we need researchers, we need providers, we need bloggers, we need educators, we need allies*

*in the media, we need activists, we need social media warriors, we need lawmakers and politicians, we need policy experts and decision makers, we need benefactors, we need philanthropists, we need visionaries. We need you. We need me. We need everyone.*

*There's a lot at stake and a lot that we already need to overcome. We should not have to worry about being taken out by our own. Please don't hurt us. Don't work against us. Don't sabotage us.*

*Work with us. Stand with us. Amplify our voices and add your own. Fight for us. Fight with us. Please.*

*And if you won't?*

*Then please, for the love of God, don't fight against us. If you aren't going to actively help us, we will survive. Not everyone can help. That doesn't make us enemies. You don't have to help us. But please just step aside. Be real with yourself, and with us - if you're not on our side, step aside. We can handle it if you're not here to help. But we don't need you to hurt, sabotage, and sideline us.*

*You don't have to be our enemy if you don't help us. But you DO become our enemy when you choose to hurt us.*

*You can't have it both ways. Choose you this day what it will be.*

*I need to know.*

Source:

<https://advocacywithoutborders.blogspot.com/2014/10/are-you-gonna-go-my-way.html>

## **October 1, 2016-December 31, 2016**

### **Quick Description (Quarter-at-a-Glance)**

- Keynote for Bellevue College's Autistics Presents.
- Autism Self Advocacy Network (ASAN) Invitational Summit on Supported Decision Making and the Transition into the Community.
- National Communications Associations 2016 Convention.
- Mayor Sylvester Turner's pledge to end HIV/AIDS Kickoff in Houston.

### Roles & Development of Praxis

- ★ Attended Autistics Present conference and **delivered keynote address**.
- ★ **Panelist** at summit in Washington, DC **addressing self-advocacy**, attended by lawmakers, lawyers, parents, caregivers, and people within the disability community. The intention of the conference was to create systems and structures so **people with disabilities can participate in society with autonomy**.
- ★ Attended as **Panelist** for National Communications Associations 2016 Convention's with the theme of "Communication's Civic Callings." As the title implies, advised **the role of communication in civic matters**.
- ★ Focusing on the cause that launched Dr. Onaiwu's activism (the **HIV** community in Houston) attending and contributing at a meeting: Advocates' Meeting with Mayor Sylvester Turner. (**Mayor Turner pledges to end HIV/AIDS.**)

### Values-at-Work

- Serving and bringing attention to the autistic community by presenting a keynote address in Bellevue, WA.
- Advocating for the disability community, as both a respected representative of the community and parent, with the intention of promoting self-advocacy and autonomy.
- Presenting at a national convention on communication to raise awareness about the power of communication to create inclusivity and understanding in civic matters.
- Working with Houston's mayor to end HIV and AIDS in Houston.

### Events Timeline

- Keynote Speaker--Autistics Present Keynote/Keynote Speaker in Bellevue, OR
  - ◆ October 1
- Summit for Autism--Invitational Summit on Supported Decision Making and the Transition into the Community/Autism Self Advocacy Network (ASAN)--Panelist in Washington, DC
  - ◆ October 18
- Communication's Civic Callings at National Communications Associations 2016 Convention--Panelist in Philadelphia, PA
  - ◆ November 9
- Advocates' Meeting with Mayor Sylvester Turner/Mayor Turner pledges to end HIV, AIDS in Houston
  - ◆ November 30

### **Featured Event**

In 2016, Dr. Onaiwu became an Executive Board Member for Autistic Self Advocacy Network (ASAN), and this role influenced and was influenced by their own advocacy organization, Advocacy Without Borders. They are distinctly different, however. The 2016 ASAN Summit was specifically to help eliminate institutionalization in favor of ways to help autistics retain autonomy.

## **ASAN's Invitational Summit on Supported Decision Making and the Transition into the Community: Summary, Conclusions, Recommendations**

The Autistic Self Advocacy Network held an Invitational Summit on Supported Decision-Making and the Transition to the Community on October 18th and October 19th, 2016. These two reports are the product of that summit.

The first report, "[Summary Paper: ASAN's Invitational Summit on Supported Decision-Making and the Transition into the Community](#)", discusses the

Source: <https://autisticadvocacy.org/policy/briefs/summit/>