

English, Rebecca

From: asia jami <asiajami@icloud.com>
Sent: Tuesday, August 22, 2023 6:16 PM
To: English, Rebecca
Cc: sarahsmithlunsford; Carrera, Lyle; Bologna, Ashley
Subject: Asia Jami written response workshop - living with ALS

The first picture is my 3 minute opener



Asia

Diagnosed at 26

Asia is a proud graduate of WSSU and U worked for Department of Public Health social worker for 8 years. Asia retired Fe 2022. Asia was diagnosed with ALS in 2022. Despite the devastating diagnosis, Asia: anything steal her her shine or her zest! Since diagnosis Asia has been to: Greece, Thailand, Mexico, Bahamas, DR, Aspen, Houston, Chicago, DC, Miami, ATL, Bos, Austin, Gatlinburg, Las Vegas, Savannah, Orleans, New York

"When I was first diagnosed with ALS it was soooo embarrassed and ashamed. A did nothing to cause it, I went to therapy process how to tell my family and friend

Asia created #AsiaDay in July 2020 who does everything her heart desires. Usual minute massage, shopping, new restaur

- Describe what living with ALS has been like for you. Have you been able to find ways to live well?

It has destroyed the relationship with my primary caregivers my mom and my brother. It has made me depressed and anxious. The only thing it has not taken is my smile. What keeps me going is doing things I love such as trying new restaurants, having a good mojito, finding candles at Homegoods, looking for new dresses at Ross and DIY projects. Traveling for live events and exploring new cities.

- How has your perspective changed over the course of your disease? As you have developed a new symptom?

I'm very optimistic because I know I'm dying I just wonder if I'm plateauing

- What, in your medical care and other aspects of your life, has contributed to living well? What has been a barrier to you living well?

I don't follow a lot of people with ALS on social media because this disease can turn people very negative and I value my peace and mental wellbeing

- Have you experienced barriers to receiving respiratory equipment or other medical equipment?

Yea there is an insurance requirement to use the trilog 4 hours daily

- If you could have anything tomorrow that would immediately improve your quality of life, what would it be?

Government funded caregivers

Access to whatever drugs I believe would improve my quality of life

Wheelchair accessible van

- What would you tell someone who was newly diagnosed with ALS or their family or other caregivers about how to live with ALS

Listen to your body and don't do anything you don't want to it's your choice when it comes to trach and feeding tube. bank your voice asap

Sent from my iPhone

On Aug 21, 2023, at 1:29 PM, English, Rebecca <REnglish@nas.edu> wrote:

Hello Asia,

Thank you for asking for clarification. The workshop is 12 – 3pm EST but this session on understanding living with ALS is the first session, 12 – 1pm. The workshop agenda is attached. You are more than welcome to stay and participate in the entire workshop, as your schedule allows. Let me know if any additional questions arise.

-Rebecca

From: asia jami <asiajami@icloud.com>

Sent: Monday, August 21, 2023 1:05 PM

To: English, Rebecca <REnglish@nas.edu>

Cc: paulseifert42@gmail.com; desi.glvz@gmail.com; sylvia.clingman@yahoo.com; sarahsmithlunsford <sarahsmithlunsford@gmail.com>; Carrera, Lyle <LCarrera@nas.edu>; Bologna, Ashley <ABologna@nas.edu>

Subject: Re: Details for Wed, Aug 23 workshop - living with ALS

Just for clarity the time requirement changed from 12—3 now it's 12-1?

Sent from my iPhone

On Aug 20, 2023, at 10:41 PM, English, Rebecca <REnglish@nas.edu> wrote:

Format: Sarah Lunsford, moderator, will introduce the panel and each of you are invited to provide **3 – 5 minute remarks** to introduce yourself and your experiences

<ALS Workshop #2 - Committee and Panelist Agenda.pdf>