



## FASD Now! Legislator Meeting Talking Points

### Meeting Outline

Welcome & Introductions -- (5 min)

FASD Overview

Constituent and/or Parent/Caregiver and/or Self Advocate Story - (3-4 min)

Subject Matter Expert (3 min)

The FASD Respect Act overview (3-4 min) Susan Carlson

Why the FASD Respect Act matters CA, CA cosponsors to date, etc. (1-2 min) Jenn Wisdahl

Q&A

Ask: Request for support (.5 min)

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Welcome XXX -- thank you so much for meeting with us today. We know you have many demands on your time and we appreciate you fitting us into your schedule. I know you received some advance background information from us and if you haven't had time to review it yet, no worries.

We're here to provide you with key information about the FASD Respect Act, HR 3946, and to offer some insight into FASD - which stands for Fetal Alcohol Spectrum Disorders.

After our meeting today, we hope you will convey this information to

Rep. ZZZ and seek her/his support as a cosponsor of the bill. We know Rep. ZZZ is committed to bipartisanship, fiscal responsibility, as well as protecting and providing for the most vulnerable among us to ensure everyone has an equal opportunity to thrive -- and the FASD Respect Act embodies these values. We want you to know that here in Northern CA, Representatives Huffman, Lee, Lofgren, Panetta, Swalwell, and Thompson, among others, have already signed on as co-sponsors. Rep. Eshoo has written a strong letter of support.

- Let me first briefly share with you who is on the call today. However, before I do so, it would be great if you could tell us a bit about yourself.

Thank you.

- So, on the call we have YYY, a constituent and parent/caregiver of a child with FASD who will share some of her family's powerful story with you.
- We also have Sid Gardner, President of Child and Family Futures, a national organization based here in CA, devoted to infant and child wellbeing, maternal health, and family preservation. Sid will provide the critical perspective of a professional with deep experience in cross-sector collaboration and systems change. He will provide additional insight into what is needed on a systems state level to address FASD.
- We also have representatives of FASD United, THE national voice for

FASD that coordinates advocacy across the country AND is the organization in the US that addresses FASD on a national level, partnering with agencies like the CDC, HRSA, NIAAA, DOD, and NIH, to increase awareness AND policy responses regarding FASD nationwide.

- Former first lady of Minnesota, Susan Carlson, who is with us today, has been a tireless advocate for FASD for decades and is the Chair of both FASD United's Legislative & Policy Committee and FASD United's Board of Directors. Susan has been closely involved with the crafting of this legislation and working with folks in both the Senate and House, on both sides of the aisle, to keep it advancing. We also have the Coordinator FASD United's Policy and Training Center and FASD United's COO, Jenn Wisdahl. Jenn supports local groups like mine to coordinate nationwide advocacy for the FASD Respect Act, and she is the parent/caregiver of three children with FASD.
- I am with FASD Now, an alliance of service providers, organizations, experts, families, and self advocates from across California advocating for FASD to be addressed in our state. In addition, FASD United has AFFILIATES across the country and I am on the Board of the affiliate in Northern California. I also am the parent/caregiver of a young adult with FASD, so this issue is quite personal for me.

BEFORE WE GET STARTED, XXX HOW FAMILIAR ARE YOU WITH FASD? WE DON'T WANT TO TAKE UP YOUR TIME WITH A QUICK OVERVIEW IF YOU ARE VERY KNOWLEDGEABLE ABOUT THE DISABILITY.

- So, briefly, FASD -- is one of the most common developmental disabilities in the US, though most folks are not familiar with it. The conservative estimate, based on prevalence studies, is that in the state of California at least 2 million children and adults currently are affected. Few of them have an accurate diagnosis and equally few receive appropriate services.

You might be interested to learn that because of how alcohol is absorbed by a pregnant person's body and the developing fetus, alcohol is more toxic to a fetus than other drugs like opioids and methamphetamine, and... it is legal. Prenatal alcohol exposure can cause lifelong deficits in all kinds of functioning, from memory to executive function to social skills. Research has begun to show that FASD is a whole body condition, with at least 400 medical conditions identified as co-morbid with FASD.

The outcomes for children and adults with FASD are astronomically better the earlier a diagnosis and services are provided. Like many people with OTHER disabilities, people on the FASD spectrum can lead fulfilling, productive lives if they receive appropriate interventions and support, and the earlier the better. As for most of California, there are no diagnostic clinics or appropriate services in the 14<sup>th</sup> Congressional District.

- Given the lack of public awareness and the lack of resources for people with FASD today, it's hard to believe this disorder was first identified about a half century ago, and one of the leading

researchers to identify it and study it is here in CA at UCSD, Dr. Kenneth Jones. There are other leading researchers of FASD in our state, as well. Despite decades of research on FASD, there continues to be terrible stigma attached to the disability. In addition, while California is home to some of the world's leading researchers of FASD, our state's response to this developmental disability lags far behind states like Alaska and Minnesota. The FASD Respect Act can help rectify that in our state, since our state will be eligible to apply for targeted funding.

- You may also find it interesting that recent research shows that although middle class college educated white women are most likely to drink alcohol during pregnancy, the long terms effects of prenatal alcohol exposure are more dire for low income communities and communities of color, due to disparities in access to health care and other services.

Do you have any questions before I continue, XXX?

- In addition, XXX, most children and adults on the FASD spectrum have an average or low average IQ, so their disability is invisible to those who don't know them well. If you met my 20 year old daughter and chatted with her superficially, you would think she is a typical young adult. Yet, like a majority of people with FASD, she has challenges with what's called adaptive functioning, the ability to master basic life skills like planning ahead, maintaining a routine - including wake up and sleep time, eating regular meals, attending to personal hygiene, not to mention, managing money and managing time... she

struggles with assessing risk and understanding other people's motives, so we still transport her everywhere...she does not have capacities that many of us take for granted, that are necessary to live safely, and fully independently in the community. Many people with FASD struggle with mental health issues like depression and anxiety, as does my daughter. She has tried to take her life several times beginning at the age of 8 years old.

- Another fact that might interest you is that recent research has shown this disability is a whole body condition -- over 400 medical conditions have now been identified as co-morbid with the neurodevelopmental aspects of FASD, from asthma and heart issues to early onset arthritis. Organs, tissue, and bones are affected by prenatal alcohol exposure, as well.

Before we continue and hear from YYY, do you have any questions ?

I will now turn it over to XXX to share her family's story.

Thank you, YYY, XXX, do you have any questions for YYY?

Before I turn it over to Sid, there are a few points I'd like to add:

- As you can imagine, FASD is over represented in certain demographics. For example, at least 1 of 3 children in foster care are affected, with high rates also seen among the chronically unhoused, chronically

unemployed, and people who cycle in and out of the juvenile and criminal legal system.

- There is tremendous waste of resources because diagnosis and services are not provided upstream, and instead our state and society are saddled with enormous unnecessary costs downstream.... Costs to address untreated mental disorders, to deal with chronically unemployed and unhoused people, to pay for court appearances and incarceration of people who are basically criminalized for having this disability, with no long term solutions. It's a terrible waste of resources that could be used for positive impact if directed in the ways that the FASD Respect Act maps out.

We especially want Rep. ZZZ to know --- An effective response to FASD requires coordination among the various systems of care, from health care and behavioral health to social services and disability services... to other systems like our education and criminal legal systems. The FASD Respect Act will provide funding for a comprehensive, coordinated approach to be put in place at the state level, including here in California.

I will now turn the mic over to Sid.

Thank you, Sid.

We now will hear concrete details about HR 3946, the FASD Respect Act, from Susan Carlson. The FASD United Policy Center has spearheaded the legislation we are here to discuss with you, and Susan has been closely

involved with the crafting of the legislation co-sponsored by Senators Murkowski and Klobuchar and Representatives Bacon and McCollom.

Thank you, Susan! XXX, do you have any questions for Susan before Jenn wraps it up for us?

Thank you so much, Susan and Jenn. XXX are there any questions you have before we end?

Thank you so much for taking the time to meet with us. We hope you will share this information with Rep. XXX and let them know we seek their valued support. The Representative's support means a great deal to us and we hope s/he will cosponsor HR 3946. I will circle back to you in a week or two to check in and see if there is any additional information that the Congressperson needs or if s/he feels ready to sign on as a cosponsor. Again, we are so appreciative of your interest and the time you shared to meet with us today.

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