## FASD Information and Resources Roxanne Chang, MD Ties for Families, South Bay

Fetal Alcohol Spectrum Disorder (FASD) is caused by prenatal alcohol exposure. No "safe" level of alcohol exposure has been identified. Any amount may harm the developing brain.

CDC: Fetal Alcohol Spectrum Disorders (FASDs). https://www.cdc.gov/ncbddd/fasd/index.html

"Red Flag" indicators for FASD:

- History of substance or alcohol use during pregnancy should trigger an immediate consideration
  of FASD
- Foster care, adopted or living with a relative
- Parent in recovery
- Multiple mental health diagnoses (especially ADHD, RAD, ODD and mood disorders)
- Discipline does not seem to work, or effects do not last
- Repeat failure despite increasing interventions
- Adaptive functioning much lower than expected for cognitive ability
- Has autistic traits (but may or may not meet full criteria for autism)
- Acts younger than expected for age
- Atypical social relationships
- Receptive language lower than expressive language (an atypical profile)

Other indicators for FASD:

- ADHD diagnosis with poor response to pharmacotherapy
- Significant scatter in cognitive testing profile
- Difficulty learning from past mistakes
- Significant variability in academic performance from day to day (or within a day).
- Testing demonstrates higher abilities than what is seen in classroom
- School dropout, suspension, expulsion

FASDs include the following specific medical diagnoses:

- Fetal Alcohol Syndrome (FAS) Has to have all physical and brain differences.
  - Poor growth
    - 3 sentinel facial features (short eye length, flat groove between lip and nose, thin upper lip)
    - Physical brain difference (small size, brain anomalies, or seizures)
    - Neurobehavioral impairment +/- cognitive (thinking/ learning) impairments
    - This is the only diagnosis that does not require documented prenatal alcohol exposure
- Partial Fetal Alcohol Syndrome (pFAS)
  - A history of prenatal alcohol exposure +
  - At least 2 of 3 facial features
  - Neurobehavioral impairment +/- cognitive impairments
  - If no history of prenatal alcohol exposure
    - At least 2 of 3 facial features
    - Growth deficiency or physical brain difference
    - Neurobehavioral impairment +/- cognitive impairments
- Alcohol-Related Neurodevelopmental Disorder (ARND)
  - Documented prenatal alcohol exposure +
  - Neurobehavioral impairment +/- cognitive impairment
- Alcohol-Related Birth Defects (ARBD)
  - Documented prenatal alcohol exposure +

 1 or more major malformations highly associated with prenatal alcohol exposure (specific heart, kidney, bone malformations, hearing loss, underdeveloped eye nerve)

Reference: Hoyme HE, Kalberg WO, Elliott AJ et al. Updated Clinical Guidelines for Diagnosing Fetal Alcohol Spectrum Disorders. Pediatrics. 2016;138(2):e20154256.

<u>A new category under study is in the Diagnostic Statistical Manual (DSM-V) to help mental health</u> <u>clinicians diagnose FASD</u>: Neuro-behavioral Disorder Associated with Prenatal Alcohol Exposure. Must have documented prenatal alcohol exposure and impairments in the following areas:

- neurocognitive function 1 or more
  - global intellectual function (IQ<70)</li>
  - impaired executive function (poor planning, organization, inflexibility, difficulty stopping behaviors)
  - impaired learning/ learning disability
  - impaired memory (problems remembering something just learned, repeat same mistakes, difficulty with long/ multi-step instructions, verbal instructions)
  - o impaired visual-spatial reasoning (left vs right, disorganized drawing, copying)
- self-regulation 1 or more
  - attention difficulties
  - o impulsivity
  - o moody, frequent meltdowns
- adaptive functioning 2 or more
  - o communication deficits
  - o impaired social communication and interaction
  - o impaired daily living skills
  - impaired motor skills

Reference: Hagan JF, Balachova T, Bertrand J et al. Neurobehavioral Disorder associated with Prenatal Alcohol Exposure. Pediatrics 2016;138(4):e20151553

#### Diagnosis requires:

- A thorough review of the following: prenatal history, birth history, growth charts, medical history, developmental history and milestones, behavioral and mental health history, learning and educational records, any IQ or other related testing of brain function.
- Further information may be collected through:
  - Measurements of weight, height, BMI, and head circumference.
  - Complete physical examination.
  - Facial examination for sentinel facial features. This may include taking a photograph for analysis and measurements.
  - Behavioral observation and learning screen.
  - Neuropsychological testing—needs to be performed with observational measures by experienced psychologist.
  - Psychoeducational testing--may be requested through your child's school.
  - o IQ and adaptive skills testing--may be requested through your local Regional Center.

**Evaluation** may include ruling out genetic conditions or looking for other associated conditions. Depending on the outcome of the initial history gathering, physical examination, and observations, your child may be referred to see a genetics specialist, brain specialist (neurologist), sleep specialist, eye specialist (ophthalmologist or optometrist), hormone specialist (endocrinologist), psychologist, and/or psychiatrist. Your child may further be referred for evaluation by an audiologist, occupational therapist, physical therapist, and/or nutritionist. (If you are being referred from TIES for Families, you already have your mental health team on board.)

**School** is often an area of struggle and stress for children with FASD if they do not receive the proper supports. We will help you work with the school to ensure understanding of your child's learning needs and best supports for learning.

Most schools are unfamiliar with how to best support learning and behavioral challenges in FASD, and underequipped to address trauma-related behavioral triggers.

Here are some recommended resources to help your child learn at school:

- https://static.fasdoutreach.ca/resources/t/trauma-informed-classroom-strategiesmanual/classroomstrategiesmanualnew%202.pdf
- o https://www.cdc.gov/ncbddd/fasd/educators.html
- o https://www.fasdhub.org.au/fasd-information/managing-fasd/what-can-teachers-do/
- o https://kidshealth.org/en/parents/fas-factsheet.html

FASD is now specifically listed under "Other Health Impairment (OHI)" eligibility for Special Education per California Education Code EC 56332 (as a result of CA SB1016 bill).

Educational rights and disability advocacy:

- o https://allianceforchildrensrights.org/
- o https://taskca.org/

# LIFE WITH FASD

https://fasdsocalnetwork.org/living-with-fasd/ https://www.cdc.gov/ncbddd/fasd/features/brenna-living-with-fasd.html https://www.cdc.gov/ncbddd/fasd/features/brenna-living-with-fasd.html https://fasdunited.org/fasd-experience/ https://www.adn.com/sponsored-content/2019/06/27/living-with-fasd-im-going-to-have-this-for-the-restof-my-life/#/questions/2209203 https://myleshimmelreich.com/

https://www.fasdhub.org.au/fasd-information/understanding-fasd/living-with-fasd/

# **Parenting**

8 Magic Keys. <u>https://www.fasdoutreach.ca/resources/all/0-9/8-magic-</u> keys#:~:text=The%208%20Magic%20Keys%20are,repitition%2C%20simplicity%2C%20and%20relationship.

FASD: Strategies not Solutions. http://www.betterendings.org/strategies\_not\_solutions.pdf

### Recommended books:

- Diane Malbin, *Trying Differently Not Harder: Fetal Alcohol Spectrum Disorders*.
- Jeff Noble, Making Sense of the Madness: An FASD Survival Guide.
- Kenny La Joy, It's OK to Be You: Living Well with FASD or Other Disabilities
- Vanessa Spiller, Explained by Brain: The FASD Workbook for Parents, Carers, and Educators (who have tried everything or don't know where to start)
- Jennifer Robinson, PhD and Laura Bedard, MFA. *My FASD Feelings: A Guide to Children's Experience with Fetal Alcohol Spectrum Disorders*.

### Other helpful websites and resources:

American Academy of Pediatrics <u>https://www.aap.org/en/patient-care/fetal-alcohol-spectrum-disorders/</u> FASD United (formerly Nofas) National affiliates/ network with information for parents, tools, policy and justice centers. <u>https://fasdunited.org/</u> Proof Alliance. https://www.proofalliance.org/

FASDNow! A California alliance of advocates. <u>https://www.fasdnow.org/</u> FASD Network of Southern California. <u>https://fasdsocalnetwork.org/</u>

#### Helpful Agencies/ Providers in Our Area:

*TIES for Families, South Bay.* Los Angeles County Department of Mental Health. Torrance, CA. (310) 533-6600

- Adoption specific mental health supports for children and families. (individual, dyadic, family, group therapies)
- Mental health care of prenatally substance-exposed infants, children, and their families.
- Trauma-informed, developmental disability and FASD informed.
- Integrated psychiatric/ pharmacological treatment services.
- Neuropsychological testing.
- FASD medical evaluation.
- Straight Medi-cal.

FASD Program at VIP, LAC+USC. Los Angeles, CA. <u>https://violenceinterventionprogram.org/about-vip/our-programs/fasd-program/</u>

- Medi-cal.
- FASD-specific child, family, mental health programs and supports.
  - TRIUMPH through the challenges
  - Families Moving Forward (FMF)
  - Individual therapy, family therapy, dyadic therapy, group therapy, individual rehabilitation, occupational therapy, case management to help children and teens with FASD. Michele Walker-Bauer, Ph.D. at mwalkerbauer@vip-cmhc.org or Ana Cardenas, LCSW at acardenas@vip-cmhc.org
- FASD medical clinic: identification and diagnosis. Jacqueline Bravo 323-409-3935 or email her at jbravo2@dhs.lacounty.gov

Harbor-UCLA Medical Center, Torrance, CA.

- Lauren Maltby, PhD. K.I.D.S. Clinic Hub. Diagnostic services for children < age 6 with open DCFS cases.
- Roxanne Chang, MD and Chiyah Lawrence, PsyD. Developmental Behavioral Pediatrics Clinic. Diagnostic evaluation, medical assessments, linkage to specialty services, and ongoing educational monitoring/ supports, pharmacotherapy. Rchang3@dhs.lacounty.gov
- Straight Medi-cal, LA Care.

# Gary Feldman, MD. Medical Director. Stramski Children's Developmental Center, Miller Children's and Women's Hospital. Long Beach, CA

- FASD diagnostic evaluation and neuropsychological testing
- Straight Medi-cal and PPO (self-refer); Medi-cal HMO requires referral from PCP.