



Stopping the *stuffing*

A freshly brewed and delicious way to learn more about speech and language therapy and occupational therapy as used in the treatment of fragile X syndrome

We recently had a 2-year-old visit from Iowa, a real cutie, but boy, was he ever a “mouth stuffer.” If you’re the parent of a child with fragile X syndrome, you’re probably very familiar with mouth stuffing, a common issue we frequently are asked about. Mouse can stuff as well—just give her a bag of Chex Mix or Famous Amos cookies and watch her go!

Mouth stuffing, by Mouse or anyone else, is an overfilling of the mouth with the selected food. For kids with FXS, it is usually an adaptive means of trying to succeed with eating. More on that later...

Mouth stuffing is a symptom of other oral motor issues that need to be addressed by your occupational therapist, speech therapist, oral facial myologist, or sometimes two or three of these professionals working in concert. We can hear you asking: “Three professionals working on the same problem?” Yes, in some regions of the U.S., speech therapists provide more of the oral motor therapy; in other places, the occupational therapist may provide this service. Oral facial myologists are the less-known experts. An oral facial myologist is a certified therapist who specializes in the precise alignment and function of the muscles of the face and mouth, utilizing specific home program-based exercises to strengthen muscles and improve oral motor function. The oral facial myologist can provide expert programming for motor-based difficulties, but may not understand the subtleties of the sensory aspects of mouth stuffing, especially in children with fragile X syndrome.

So why do these kids tend to overfill their mouths? Because it simply tastes so good? Not likely!

Remember that children with FXS are plagued by low muscle tone and poor oral sensory awareness, as well as poor oral-sensory-motor control of the fine movements of their

mouth. What a package of problems to try to manage! And how smart of these kids to figure out that given the diminished motor and sensory skills they have to work with, if they fill up the space, the work is easier and they receive more feedback, which will lead to success .

Let’s get back to that 2-year-old. We pulled out our favorite trick (once Tracy got it away from Mouse, anyway): Pop Rocks! You know—that fizzy, bubbly candy that goes POP! in a kid’s mouth as soon as it gets wet. What a success!

Your first thought when you think about Pop Rocks might be, “Are you serious—put something that “overstimulating” in a toddler’s mouth? These gals really are nuts! Contrary to intuition, Pop Rocks may be the “just right” input to wake up that mouth and get those muscles activated. (Note: your intuition that we are a bit nuts may still be on target.)

For our visiting 2-year-old, we saw an immediate change in oral awareness—which resulted in a corresponding increase in oral movements (both quality and quantity)—as he explored the Pop Rocks with his tongue, cheek and lips. All this with only four little Pop Rocks!

So, is the use of Pop Rocks going to solve all mouth stuffing issues? No. A well-considered program of oral motor play, oral sensory diet, and visual supports to manage oral portions is more the ticket. So here are some suggestions for you and your therapists to follow through on such a program. This is a limited list of things we have found particularly useful, but there are also some wonderful resources in OT and speech therapy catalogues.

ORAL MOTOR PLAY

- Play puppy dog by having your child bite on a frozen, wet wash rag as you try to tug it away as he clenches it.
- Provide your child with a variety of “chew toys” that provide resistance in the mouth.
- Include sucking and blowing at meals with different sized straws. (Mouse loves those funky straws from the Asian Tapioca Tea House. Tracy is inclined to the twisty straw.)

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- Bubbles, bubbles, bubbles, and not just the kind in the little 99-cent bottle. Blow bubbles while in the bathtub, blow in a bowl of milk or pudding (not a cup; we don't want to teach a behavior we have to undo). Just blow.

ORAL SENSORY DIET

- We have found use of the Wilbarger oral pressure protocol to be incredibly valuable for most kids exhibiting mouth stuffing. This is interesting, considering that the method was devised as a treatment for oral hypersensitivity (oral defensiveness). You have to have direct training from a therapist trained in the Wilbarger techniques to know how to use this strategy—we can't teach it to you in this forum, but ask your therapist about it.
- Include crunchy and chewy-resistive foods at each meal and snack. The frequency of oral sensory input—scheduled not just once or on occasion but about 6-8 times each day—is the key to this technique.

VISUAL SUPPORTS

- Put only a single bite-size portion of the foods most commonly overstuffing in front of the child until that portion size is learned, then gradually increase.

- Use a template on the plate showing the bite-sized portion (a laminated photo?) or have this on a card in front of the child next to her plate to visually cue her on the right amount.
- Model, model, model—have the whole family talk about and physically demonstrate what portions are best for different (especially new) foods.

As for us, we plan to continue to stuff ourselves silly at every opportunity! 

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Member Survey Results *continued from page 5*

2) *Awareness (spreading the word about Fragile X):*

- 22 (14%) ranked this as #1
- 30 (19%) ranked this as #2
- 38 (24%) ranked this as #3
- 36 (23%) ranked this as #4
- 24 (15%) ranked this as #5

3) *Education (organizing conferences, developing our website, publishing books, pamphlets, etc.):*

- 32 (20%) ranked this as #1
- 32 (20%) ranked this as #2
- 48 (30%) ranked this as #3
- 26 (16%) ranked this as #4
- 18 (11%) ranked this as #5

4) *Research (providing large grants for treatment or clinical research and for basic science research into Fragile X):*

- 35 (22%) ranked this as #1
- 39 (25%) ranked this as #2

35 (22%) ranked this as #3

31 (20%) ranked this as #4

22 (14%) ranked this as #5

5) *Legislative Advocacy (organizing the effort to convince the government to spend more money on Fragile X research and treatment):*

21 (13%) ranked this as #1

33 (21%) ranked this as #2

29 (18%) ranked this as #3

32 (20%) ranked this as #4

44 (28%) ranked this as #5

Didn't receive a survey? Please make sure that you are a current member of the National Fragile X Foundation and that we have your correct email address.