

The purpose of this survey is to learn about biomedical treatments that parents of children with autism use. We would like to know what, if any, treatments you have tried with your child, and whether you found it to be helpful or not.

We are interested in both traditionally prescribed pharmaceuticals as well as complementary and alternative medicine (CAM). CAM is a broad term that refers to a variety of products, treatments, and practices that are not generally considered part of conventional medicine such as supplements, special diets, physical interventions, and more (National Center for Complementary and Integrative Health). For the purposes of this survey, we will only be focusing on biomedical products and treatments.

SECTION 1: Demographic and Diagnostic Information

1. Please indicate if you are the child's:

- Biological Mother
- Biological Father
- Other Primary Caregiver (please specify _____)

2. What is your year of birth? _____

3. What is your current marital status?

- Married
- Widowed
- Divorced
- Separated
- Never Married

4. What is the highest level of education completed by the child's mother?

- Less than high school degree
- High school degree or equivalent (e.g. GED)
- Some college but no degree
- Trade/technical/vocational training/military training
- Associate degree
- Bachelor's degree
- Master's degree
- Professional degree
- Doctorate degree

5. What is the highest level of education completed by the child's father?

- Less than high school degree
- High school degree or equivalent (e.g. GED)
- Some college but no degree
- Trade/technical/vocational training/military training
- Associate degree
- Bachelor's degree
- Master's degree
- Professional degree
- Doctorate degree

6. What was the sex of the child when they were born?

- Male
- Female

7. How old is your child? _____years

8. What is your child's race?

- | | |
|---|--|
| <input type="checkbox"/> American Indian or Alaska Native | <input type="checkbox"/> Native Hawaiian or Other Pacific Islander |
| <input type="checkbox"/> Asian | <input type="checkbox"/> White |
| <input type="checkbox"/> Black or African American | <input type="checkbox"/> Other_____ |

9. What is your child's ethnicity?

- Hispanic
- Non-Hispanic

10. In what setting does your child currently receive schooling?

- Public school
- Private school
- Special education school
- Residential school
- Home schooled
- Not currently in school

11. Aside from your child's primary autism symptoms (difficulties with language, social interactions, and restricted or repetitive interests or behaviors), what other health issues does your child struggle with?

- Digestive problems (e.g., constipation, diarrhea, vomiting, reflux)
- Neurological problems (e.g., headaches, tics, seizures)
- Sleep problems (e.g., trouble falling asleep or staying asleep)
- Immune system problems (e.g., allergies/hay fever, eczema, food sensitivities)
- Genetic disorders (e.g., Landau-Kleffner, Fragile X, Down's syndrome, etc.)
- Metabolic disorders (e.g., PKU, mitochondrial disorders)
- Psychiatric disorders (e.g., anxiety, OCD, ADD, ADHD, depression, bipolar disorder, etc.)
- Challenging behaviors (e.g. aggression, self-injury, elopement/leaves unexpectedly, etc.)
- Other _____

SECTION 2: Alternative Treatments

12. Have you used ANY complementary or alternative medicine (CAM) to help improve your child's health or reduce their autism symptoms? (CAM could be vitamin or mineral supplements, special diets, chelation, antifungals for yeast, craniosacral therapy, music therapy, biofeedback, hyperbaric oxygen therapy, etc.)
- Yes
 - No

SECTION 3: Treatments

13. *Please indicate all the following treatments that you have **ever** used for your child with autism (include any route of administration e.g. pill, spray, injection, etc.):

| | | |
|--------------------------------------|--|--|
| <input type="checkbox"/> Vitamin A | <input type="checkbox"/> Inositol (B8) | <input type="checkbox"/> Vitamin E |
| <input type="checkbox"/> Vitamin B1 | <input type="checkbox"/> P5P | <input type="checkbox"/> Vitamin K |
| <input type="checkbox"/> Vitamin B2 | <input type="checkbox"/> Methyl B-12 | <input type="checkbox"/> B-complex vitamin |
| <input type="checkbox"/> Vitamin B3 | <input type="checkbox"/> Folic | <input type="checkbox"/> Multi-vitamin |
| <input type="checkbox"/> Vitamin B5 | <input type="checkbox"/> Folinic acid | <input type="checkbox"/> Multi-Mineral |
| <input type="checkbox"/> Vitamin B6 | <input type="checkbox"/> Vitamin C | |
| <input type="checkbox"/> Biotin (B7) | <input type="checkbox"/> Vitamin D | |

14. *Please indicate all the following treatments that you have **ever** used for your child with autism (include any route of administration e.g. pill, spray, injection, etc.):

| | |
|---|--|
| <input type="checkbox"/> Chelation- DMSA | <input type="checkbox"/> Alpha Lipoic Acid |
| <input type="checkbox"/> Chelation- DMPS | <input type="checkbox"/> Glutathione |
| <input type="checkbox"/> Chelation- EDTA | <input type="checkbox"/> N-Acetyl Cysteine |
| <input type="checkbox"/> Chelation- N-acetyl cysteine | <input type="checkbox"/> TTFD |

15. *Please indicate all the following treatments that you have **ever** used for your child with autism (include any route of administration e.g. pill, spray, injection, etc.):

| | |
|------------------------------------|--|
| <input type="checkbox"/> Melatonin | <input type="checkbox"/> Cannabidiol (CBD) oil |
| <input type="checkbox"/> Secretin | <input type="checkbox"/> Fish oil supplements, Omega-3 fatty acids |
| <input type="checkbox"/> Oxytocin | <input type="checkbox"/> Essential oils |

16. *Please indicate all the following treatments that you have **ever** used for your child with autism (include any route of administration e.g. pill, spray, injection, etc.):

| | |
|---|---|
| <input type="checkbox"/> Gluten-free Casein-free (GFCF) | <input type="checkbox"/> Feingold Diet |
| <input type="checkbox"/> Gluten free (GF) only | <input type="checkbox"/> Ketogenic diet |
| <input type="checkbox"/> Casein free (CF) only | |

***Items 13-16 branch logic:** For each selection made, subjects will be prompted to answer the following questions:

- A. How was the treatment given?
- Taken by mouth and swallowed or chewed
 - Placed under the tongue or between the gums and cheek
 - Given by injection (by needle through the skin)
 - Sprayed into the nose
 - Applied on the skin
 - Suppository
 - Other: _____
- B. Who first suggested the treatment?
- Medical professional
 - Parent or other caregiver
 - Other relative or friend (non-caregiver)
 - Other _____
- C. Was this treatment prescribed by a medical professional?
- Yes
 - No
- D. How was the treatment obtained?
- Prescription filled at pharmacy
 - Over-the-counter purchase at pharmacy or another store
 - Provided by medical professional
 - Online order
 - Other _____
- E. When was this treatment used (select all that apply):
- Within the past 3 months
 - Between 3-12 months ago
 - More than 12 months ago
- F. How did you pay for this treatment?
- Covered by insurance only
 - Paid out-of-pocket only
 - Both covered by insurance and paid out-of-pocket
- G. To the best of your knowledge, was this treatment intended to address your child's:
- Difficulties with language and/or social interactions**

- Restricted or repetitive interests or behaviors**
- Aggression
- Anxiety
- Depression
- Hyperactivity
- Inattention
- Other mental health issues
- Other physical health issues
- Unsure

H. Based on your experience, how would you rate the effectiveness of this treatment?

- Very harmful Slightly harmful No change Slightly helpful Very helpful

I. ****Item G branch logic:** Subjects who select at least one ** option will be prompted to answer question I:

Based on your experience, how would you rate the effectiveness of this treatment on improving your child's difficulties with language, social interactions, and/or restricted or repetitive interests or behaviors?

- Very harmful Slightly harmful No change Slightly helpful Very helpful

17. *Please indicate any FDA approved prescription medication(s) that your child with autism has taken:

| | |
|---|--|
| <input type="checkbox"/> Zoloft® (Also called sertraline) | <input type="checkbox"/> Effexor® (Also called venlafaxine) |
| <input type="checkbox"/> Prozac® (Also called fluoxetine) | <input type="checkbox"/> Wellbutrin® (Also called bupropion) |
| <input type="checkbox"/> Paxil® (Also called paroxetine) | <input type="checkbox"/> BuSpar® (Also called buspirone) |
| <input type="checkbox"/> Celexa® (Also called citalopram) | <input type="checkbox"/> Lexapro® (Also called escitalopram) |
| <input type="checkbox"/> Remeron® (Also called mirtazapine) | |

18. *Please indicate any FDA approved prescription medication(s) that your child with autism has taken:

| | |
|---|---|
| <input type="checkbox"/> Risperdal® (Also called risperidone) | <input type="checkbox"/> Clozaril® (Also called clozapine) |
| <input type="checkbox"/> Abilify® (Also called aripiprazole) | <input type="checkbox"/> Haldol® (Also called haloperidol) |
| <input type="checkbox"/> Seroquel (Also called quetiapine) | <input type="checkbox"/> Mellaril® (Also called thioridazine) |
| <input type="checkbox"/> Zyprexa® (Also called olanzapine) | <input type="checkbox"/> Orap® (Also called pimozide) |

19. *Please indicate any FDA approved prescription medication(s) that your child with autism has taken:

| | |
|--|--|
| <input type="checkbox"/> Depakote® (Also called valproic acid) | <input type="checkbox"/> Eskalith® (Also called lithium carbonate) |
| <input type="checkbox"/> Tegretol® (Also called carbamazepine.) | <input type="checkbox"/> Lithobid® (Also called lithium carbonate) |
| <input type="checkbox"/> Cibalith-S® (Also called lithium citrate) | <input type="checkbox"/> Lamictal® (Also called lamotrigine) |

20. *Please indicate any FDA approved prescription medication(s) that your child with autism has taken:

| | |
|---|--|
| <input type="checkbox"/> Ritalin® (Also called methylphenidate) | <input type="checkbox"/> Dexedrine® (Also called dextroamphetamine) |
| <input type="checkbox"/> Concerta® (Also called methylphenidate) | <input type="checkbox"/> Dextrostat® (Also called dextroamphetamine) |
| <input type="checkbox"/> Metadate® ER (Also called methylphenidate) | <input type="checkbox"/> Focalin® (Also called dexmethylphenidate) |
| <input type="checkbox"/> Adderall® (Also called amphetamine) | <input type="checkbox"/> Strattera® (Also called atomoxetine) |
| <input type="checkbox"/> Tenex® (Also called guanfacine) | <input type="checkbox"/> Catapres® (Also called clonidine) |
| <input type="checkbox"/> Kapvay® (Also called clonidine) | <input type="checkbox"/> Intuniv® (Also called guanfacine) |
| <input type="checkbox"/> Cylert® (Also called pemoline) | <input type="checkbox"/> Daytrana® (Also called methylphenidate transdermal patch) |
| <input type="checkbox"/> Vyvanse® (Also called lisdexamfetamine) | <input type="checkbox"/> Jornay PM® (Also called methylphenidate) |

***Item 17-20 branch logic:** For each selection made, subjects will be prompted to answer the following questions:

A. When was this treatment used (select all that apply):

- Within the past 3 months
- Between 3-12 months ago
- More than 12 months ago

B. Based on your experience, how would you rate the effectiveness of this treatment?

- Very harmful Slightly harmful No change Slightly helpful Very helpful

21. Please list any other biomedical treatment(s) that you have **ever** used for your child with autism:

