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?
	* American Indian or Alaska Native
	* Asian
	* Black or African American
	* Native Hawaiian or Other Pacific Islander
	* White
	* 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

1. 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

1. \*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.):

|  |  |  |
| --- | --- | --- |
| * Vitamin A
 | * Inositol (B8)
 | * Vitamin E
 |
| * Vitamin B1
 | * P5P
 | * Vitamin K
 |
| * Vitamin B2
 | * Methyl B-12
 | * B-complex vitamin
 |
| * Vitamin B3
 | * Folic
 | * Multi-vitamin
 |
| * Vitamin B5
 | * Folinic acid
 | * Multi-Mineral
 |
| * Vitamin B6
 | * Vitamin C
 |  |
| * Biotin (B7)
 | * Vitamin D
 |  |

1. \*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.):

|  |  |
| --- | --- |
| * Chelation- DMSA
 | * Alpha Lipoic Acid
 |
| * Chelation- DMPS
 | * Glutathione
 |
| * Chelation- EDTA
 | * N-Acetyl Cysteine
 |
| * Chelation- N-acetyl cysteine
 | * TTFD
 |

1. \*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.):

|  |  |
| --- | --- |
| * Melatonin
 | * Cannabidiol (CBD) oil
 |
| * Secretin
 | * Fish oil supplements, Omega-3 fatty acids
 |
| * Oxytocin
 | * Essential oils
 |

1. \*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.):

|  |  |
| --- | --- |
| * Gluten-free Casein-free (GFCF)
 | * Feingold Diet
 |
| * Gluten free (GF) only
 | * Ketogenic diet
 |
| * Casein free (CF) only
 |  |

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

1. 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: \_\_\_\_\_\_\_\_
2. Who first suggested the treatment?
	* Medical professional
	* Parent or other caregiver
	* Other relative or friend (non-caregiver)
	* Other \_\_\_\_\_\_\_\_
3. Was this treatment prescribed by a medical professional?
	* Yes
	* No
4. 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\_\_\_\_\_\_\_\_\_\_
5. When was this treatment used (select all that apply):
	* Within the past 3 months
	* Between 3-12 months ago
	* More than 12 months ago
6. 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
7. 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
8. Based on your experience, how would you rate the effectiveness of this treatment?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| * Very harmful
 | * Slightly harmful
 | * No change
 | * Slightly helpful
 | * Very helpful
 |

1. \*\****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
 |

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

|  |  |
| --- | --- |
| * Zoloft**®** (Also called sertraline)
 | * Effexor**®** (Also called venlafaxine)
 |
| * Prozac**®** (Also called fluoxetine)
 | * Wellbutrin**®** (Also called buproprion)
 |
| * Paxil**®** (Also called paroxetine)
 | * BuSpar**®** (Also called buspirone)
 |
| * Celexa**®** (Also called citalopram)
 | * Lexapro**®** (Also called escitalopram)
 |
| * Remeron**®** (Also called mirtazapine)
 |  |

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

|  |  |
| --- | --- |
| * Risperdal**®** (Also called risperidone)
 | * Clozaril**®** (Also called clozapine)
 |
| * Abilify**®** (Also called aripiprazole)
 | * Haldol**®** (Also called haloperidol)
 |
| * Seroquel (Also called quetiapine)
 | * Mellaril**®** (Also called thioridazine)
 |
| * Zyprexa**®** (Also called olanzapine)
 | * Orap**®** (Also called pimozide)
 |

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

|  |  |
| --- | --- |
| * Depakote**®** (Also called valproic acid)
 | * Eskalith**®** (Also called lithium carbonate)
 |
| * Tegretol**®** (Also called carbamazepine.)
 | * Lithobid**®** (Also called lithium carbonate)
 |
| * Cibalith-S**®** (Also called lithium citrate)
 | * Lamictal**®** (Also called lamotrigine)
 |

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

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

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

1. When was this treatment used (select all that apply):
	* Within the past 3 months
	* Between 3-12 months ago
	* More than 12 months ago
2. Based on your experience, how would you rate the effectiveness of this treatment?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| * Very harmful
 | * Slightly harmful
 | * No change
 | * Slightly helpful
 | * Very helpful
 |

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

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_