AUTISM TREATMENT EFFECTIVENESS SURVEY

Preliminary Results

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Personal Background

- Director of Autism/Asperger’s Research Program at ASU
- President, Autism Nutrition Research Center
- President of Greater Phoenix Chapter of ASA
- Co-leader of Science Advisory Committee of Autism Research Institute
- Chair, Scientific Advisory Board, Neurological Health Foundation
- Father of adult daughter with autism
- Autism research includes:
  - Nutrition: vitamins, minerals, fatty acids, amino acids, ribose
  - Metabolism: glutathione, methylation, sulfation, oxidative stress
  - Mitochondria – ATP, muscle strength, carnitine
  - Toxic Metals and Chelation
  - Gastrointestinal Problems & Treatments
  - Immunology
  - Seizures
  - Vocational Issues
Prof. Adams is the President of the Autism Nutrition Research Center (ANRC), a non-profit which produces ANRC Essentials, a vitamin/mineral supplement for children and adults with autism based on research he led at ASU.

Prof. Adams serves as a volunteer, and does not receive any salary or royalties from sales of ANRC Essentials.
The Autism Research Institute previously published a rating of many medications, nutritional supplements, and restricted diets based on a survey of over 27,000 families (www.autism.com, ARI Publication 34).

Those ratings used an overall rating of 1 (much worse) to 6 (much better), but did not rate individual symptoms.
Survey Goals

• Develop ratings for medications, nutritional supplements, diets, and therapies, including
  • Overall benefit and adverse effects
  • Specific benefits and specific adverse effects

• Determine highest-rated treatments for different symptoms and behaviors (language, social, sleep, anxiety, etc.)
Advantages and Limitations of this Survey

Advantages
- Compares all treatments with the same rating scales
- Improvements and adverse effects are rated independently
- Many of the treatments have not been studied for people with ASD
- Most research studies are short-term – some participants in this survey have used these treatments for years
- Can help parents identify promising treatment options
- Can help researchers plan future studies

Limitations
- Survey data is subject to “placebo effect”
- Retrospective (based on memory)
- Survey data is less reliable than randomized, double-blind, placebo-controlled studies
- We are only able to present averages
Methods

The survey was advertised nationally via Facebook ads, and with the help of over 50 autism groups throughout the country.

For the preliminary analysis, 783 responses were gathered from primary caregivers of individuals with ASD (82%) and adults with ASD (12%).

Treatments with less than 20 responses were excluded from the preliminary analysis.
This survey is divided into seven sections:

- Medical History
- Psychiatric and Seizure Medications
- Other Medications
- Nutritional Supplements
- Diets
- Therapies
- K-12 Education

The survey included 169 medications, 126 nutritional supplements, 18 diets, and 23 therapies. For each treatment selected, respondents were asked about the level of benefit and adverse effects and the symptoms affected.

1 = “No benefit”
2 = “Slight benefit”
3 = “Moderate benefit”
4 = “Good benefit”
5 = “Great benefit”

1 = “No adverse effects”
2 = “Mild adverse effects”
3 = “Moderate adverse effects”
4 = “Severe adverse effects”
22. How would you rate the overall **benefits** of Adderall? (later you will be asked about adverse effects)

- No benefit
- Slight benefit
- Moderate benefit
- Good benefit
- Great benefit

23. If Adderall caused any adverse effects, please rate their severity.

- No adverse effects
- Mild adverse effects
- Moderate adverse effects
- Severe adverse effects

What were the **adverse** effects of Adderall? (please list only the **primary** ones)

- General worsening, no one specific symptom
- Aggression/Agitation
- Anxiety
- Bedwetting/Bladder Control
- Behavior problems

Please check the **primary** symptoms that Adderall improved – you can check one or more.

- General benefit, no one particular symptom
- Aggression/Agitation
- Anxiety
Possible Benefits*

- Aggression/Agitation
- Anxiety
- Attention
- Cognition (ability to think)
- Constipation
- Depression
- Diarrhea
- Eczema/Skin problem
- General benefit, no one particular symptom
- Health (fewer illnesses and/or less severe illnesses)
- Hyperactivity
- Irritability
- Language/Communication
- Lethargy (easily tired)
- OCD
- Reflux/Vomiting
- Seizures
- Self-Injury
- Sleep (falling asleep)
- Sleep (staying asleep)
- Social Interaction and Understanding
- Stimming/Perseveration/Desire for Sameness
- Tics/Abnormal movements

Additional Therapy Benefits

- Balance
- Body Awareness
- Emotion Regulation
- Fine Motor Coordination
- Gross Motor Coordination/Muscle Tone
- Play
- Reading
- Self-Care Skills
- Sensory Sensitivity
- Willingness to try new foods

* Not all benefits were shown for each treatment, only those applicable. A few other benefits were included for specific treatments, such as “bacteria-related illness” for antibiotics.
Possible Adverse Effects

• General worsening, no one specific symptom
• Aggression/Agitation
• Anxiety
• Bedwetting/Bladder Control
• Behavior problems
• Decreased cognition (difficulty thinking/remembering)
• Depression
• Dizziness/Unsteadiness
• Dry mouth
• Fatigue/Drowsiness
• Gastrointestinal problems
• Headache/Migraine
• Hyperactivity
• Irritability
• Liver/Kidney problem
• Loss of appetite
• Nausea
• Rash
• Seizures
• Self-injury
• Sleep Problems
• Stimming/Perseveration/Desire for Sameness
• Tics/Abnormal movements
• Weight gain
• Weight loss
Demographics

Current Age
- Children (ages <13): 43%
- Teens (ages 13-18): 25%
- Adults (ages 19+): 32%

Diagnosis
- Autism: 42%
- High-Functioning Autism: 13%
- ASD: 17%
- Asperger’s: 17%
- PDD-NOS: 5%
- No current diagnosis: 2%
- No official diagnoses: 3%
- Other: 1%

Country
- 93% US vs. 7% foreign

Gender
- Male: 71%
- Female: 29%

Developmental History
- Major regression: 22%
- Plateau in development: 22%
- Major regression and a plateau: 13%
- Early onset: 32%
- Other: 11%
Most Commonly Used Treatments
Psychiatric Medications

Most beneficial to least beneficial:

- Catapres
- Buspar
- Prozac
- Intuniv
- Zoloft
- Lexapro
- Celexa
- Abilify
- Focalin
- Risperdal
- Seroquel
- Ritalin
- Strattera
- Adderall

Most Common Treatment

- Catapres
- Ritalin
- Adderall
Catapres
(Clondine)

Most Benefited Symptoms

Most Common Adverse Effects

n = 61
Adderall
(Amphetamin, Dextroamphetamine)

Most Benefited Symptoms

- Attention: 40%
- Hyperactivity: 20%
- Cognition: 20%
- Anxiety: 10%
- Social Interaction: 10%

Most Common Adverse Effects

- Aggression/Agitation: 40%
- Anxiety: 30%
- Irritability: 20%
- Behavior problems: 10%
- Loss of appetite: 10%

n = 70
Prozac
(Fluoxetine, Sarafem)

Most Benefited Symptoms

- Anxiety: 40%
- Depression: 30%
- Aggression/Agitation: 20%
- Irritability: 10%
- OCD: 0%

Most Common Adverse Effects

- Cognition: 10%
- Depression: 10%
- Weight gain: 10%
- Aggression/Agitation: 10%
- Anxiety: 0%

n = 66
Risperdal
(Risperidone)

Most Benefited Symptoms

Most Common Adverse Effects

n = 87
Ritalin
(Daytrana, Methylphenidate)

Most Benefited Symptoms

Most Common Adverse Effects

n = 61
Seizure Medications

Most beneficial  Lamictal  Valium  Tegretol  Depakote  Klonopin  Topamax

Least beneficial
Lamictal (Lamotrigine)

Most Benefited Symptoms

Seizures: 30%
Aggression/Agitation: 20%
Anxiety: 10%
Irritability: 10%
Depression: 10%

Most Common Adverse Effects

Sleep Problems: 10%
Weight gain: 10%
Cognition: 10%
Aggression/Agitation: 10%
Depression: 10%

n = 61
Essential Fatty Acids

- Cod Liver Oil
- Omega-3
- Omega-6
- Fish Oil
- Flax Seed Oil

<table>
<thead>
<tr>
<th>Benefit</th>
<th>Adverse</th>
</tr>
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<tbody>
<tr>
<td>Cod Liver Oil</td>
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<tr>
<td>Omega-3</td>
<td>2</td>
</tr>
<tr>
<td>Omega-6</td>
<td>1</td>
</tr>
<tr>
<td>Fish Oil</td>
<td>1</td>
</tr>
<tr>
<td>Flax Seed Oil</td>
<td>1</td>
</tr>
</tbody>
</table>
Cod Liver Oil
Highest Rated Essential Fatty Acid

Most Benefited Symptoms

- Cognition: 30%
- General benefit: 20%
- Attention: 10%
- Language/Communication: 10%
- Constipation: 5%

Adverse Effects

- Gastrointestinal problems: 10%
- Irritability: 10%
- Tics/Abnormal movements: 5%

n = 49
Sleep Treatments

Bar chart showing benefits and adverse effects of Melatonin, 5-HTP, and Valerian Root.

- Melatonin: High benefit, moderate adverse effect
- 5-HTP: Low benefit, low adverse effect
- Valerian Root: Moderate benefit, low adverse effect
Melatonin
Highest Rated Sleep Medication

Most Benefited Symptoms

Most Common Adverse Effects

n = 152
Gastrointestinal Treatments Usage

Probiotics: 55%
Nystatin: 15%
Miralax: 10%
Diflucan: 10%
Magnesium Citrate: 10%
Digestive Enzyme: 10%
Vitamin C: 10%
Steroids: 10%
Dulcolax: 10%
Prevacid: 10%
Prilosec: 10%
Colace: 10%
Oregano Concentrate: 5%
Gastrointestinal Medications and Nutritional Supplements
Magnesium Citrate
Highest Rated GI Medication/Nutritional Supplement

Most Benefited Symptoms

Most Common Adverse Effects

n = 44
Antifungals

- **Diflucan**
- **Oregano concentrate**
- **Saccharomyces boulardii**
- **Nystatin**

Bar chart showing benefit and adverse effects for different antifungals.
Diflucan
Highest Rated Antifungal

Most Benefited Symptoms

- Fungal infections: 70%
- Attention: 20%
- Eczema/Skin problem: 15%
- Irritability: 15%
- Social Interaction: 10%

Most Common Adverse Symptoms

- Gastrointestinal problems: 10%
- Behavior problems: 5%
- Irritability: 5%
- Liver/Kidney problem: 5%
- Sleep Problems: 5%

n = 58
Probiotics

**Most Benefited Symptoms**

- General benefit: 40%
- Constipation: 30%
- Diarrhea: 20%
- Health: 10%
- Attention: 0%

**Most Common Adverse Effects**

- Gastrointestinal problems: 50%
- General worsening: 40%
- Aggression/Agitation: 30%
- Anxiety: 20%
- Behavior problems: 10%

n = 176
Vitamins

- Injected Vitamin B12
- Vitamin D
- CoQ10
- Vitamin E
- Oral Vitamin B12
- Vitamin C
- Biotin
- DMG

**Benefit**

- **Adverse**

![Bar chart showing benefits and adverse effects of various vitamins.](chart-url)
Injected Vitamin B12
Highest Rated Vitamin

Most Benefited Symptoms

- General benefit: 30%
- Cognition: 20%
- Language/Communication: 20%
- Lethargy (easily tired): 20%
- Attention: 10%

Adverse Effects

- Hyperactivity: 10%
- Sleep Problems: 10%

n = 23
Minerals

- Magnesium
- Iron
- Zinc
- Calcium

Benefit
Adverse
Magnesium
Highest Rated Mineral

Most Benefited Symptoms

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>General benefit</td>
<td>50%</td>
</tr>
<tr>
<td>Constipation</td>
<td>40%</td>
</tr>
<tr>
<td>Anxiety</td>
<td>20%</td>
</tr>
<tr>
<td>Irritability</td>
<td>10%</td>
</tr>
<tr>
<td>Sleep (falling asleep)</td>
<td>10%</td>
</tr>
</tbody>
</table>

Adverse Effects

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Behavior problems</td>
<td>0%</td>
</tr>
<tr>
<td>Hyperactivity</td>
<td>0%</td>
</tr>
</tbody>
</table>

n = 69
Special Multivitamins for ASD

**Most Benefited Symptoms**

- General benefit: 60%
- Health: 30%
- Attention: 20%
- Cognition: 20%
- Language/Communication: 10%

**Most Common Adverse Effects**

- General worsening: 50%
- Aggression/Agitation: 40%
- Bedwetting/Bladder Control: 30%
- Behavior problems: 20%
- Decreased cognition: 10%

n = 51
Multivitamins

Benefits

Special Multivitamin for ASD

<table>
<thead>
<tr>
<th>Benefits</th>
<th>n = 51</th>
</tr>
</thead>
<tbody>
<tr>
<td>General benefit</td>
<td>60%</td>
</tr>
<tr>
<td>Health</td>
<td>30%</td>
</tr>
<tr>
<td>Attention</td>
<td>20%</td>
</tr>
<tr>
<td>Cognition</td>
<td>20%</td>
</tr>
<tr>
<td>Language/Communication</td>
<td>10%</td>
</tr>
</tbody>
</table>

Generic Multivitamin

<table>
<thead>
<tr>
<th>Benefits</th>
<th>n = 185</th>
</tr>
</thead>
<tbody>
<tr>
<td>General benefit</td>
<td>60%</td>
</tr>
<tr>
<td>Health</td>
<td>30%</td>
</tr>
<tr>
<td>Attention</td>
<td>10%</td>
</tr>
<tr>
<td>Cognition</td>
<td>10%</td>
</tr>
<tr>
<td>Language/Communication</td>
<td>0%</td>
</tr>
</tbody>
</table>
Carnitine

Most Benefited Symptoms

- General benefit: 30%
- Lethargy (easily tired): 20%
- Health: 10%
- Attention: 10%
- Cognition: 10%

n = 28

Adverse Effects

- General worsening: 10%
- Aggression/Agitation: 10%
- Irritability: 10%
- Sleep Problems: 10%
Epsom Salts

Most Benefited Symptoms

- General benefit: 30%
- Anxiety: 25%
- Sleep (falling asleep): 20%
- Hyperactivity: 15%
- Irritability: 10%

Most Common Adverse Effects

- Aggression/Agitation: 0%
- Anxiety: 0%
- Headache/Migraine: 0%
- Irritability: 0%
- Rash: 0%

n = 59
Essential Oils

**Most Benefited Symptoms**

- Anxiety: 50%
- Aggression/Agitation: 30%
- Health: 20%
- Irritability: 10%
- Sleep (falling asleep): 0%

**Adverse Effect**

- Rash: 0%

**Overall Benefit Score**

- Overall Adverse Score

\[ n = 41 \]
Diets

- Healthy diet
- Feingold Diet
- Low-Sugar Diet
- Gluten-Free and Casein-Free
- Food-Avoidance (food testing)
- Food-Avoidance (observation)
- Corn-free Diet
- Soy-free Diet
- Gluten-Free Diet
- Casein-Free Diet

**Benefit**

**Adverse**
Healthy Diet
Highest Rated Diet

Most Benefited Symptoms

Adverse Effect

n = 75
Therapies

Overall Benefit Scores

- Exercise: 4
- Physical Therapy: 3
- Occupational Therapy: 3
- Speech Therapy: 3
- Sensory Integration: 3
- Applied Behavior Analysis: 3
- Music Therapy: 3
- Floortime: 3
- Aquatherapy: 3
- Horse Therapy: 3
- Feeding Therapy: 3
- Listening Program: 2
Applied Behavior Analysis

Most Benefited Symptoms

Adverse Effects

n = 129
Exercise

Most Benefited Symptoms

- Body Awareness: 70%
- Gross Motor Coordination/Muscle Tone: 60%
- Balance: 50%
- Fine motor coordination: 40%
- Attention: 30%

n = 59
Effectiveness Scores

Effectiveness score =

\[(\text{overall benefit rating of 0-4}) \times (\% \text{ of treatment users reporting improvement in that symptom})\]

This gives the range 0 (not at all effective) to 4 (highly effective for 100\% of respondents).

Limitation: If a higher \% of people using a medication have a particular symptom (i.e., higher rate of seizures in those using anti-seizure meds), then that will tend to result in higher effectiveness scores for the specialized treatments, so comparisons across categories of treatments (i.e. anti-seizure meds vs. diets) need to be made cautiously.
Best Treatments for **Language/Communication**

**Effectiveness Scores**

- **Speech Therapy**
- **Applied Behavior Analysis**
- **Floortime**
- **Music Therapy**
- **Gluten-Free and Casein-Free**
- **Horse Therapy**
- **Injected Vitamin B12**
- **Exercise**
- **Occupational Therapy**
- **Feeding Therapy**
Best Treatments for Social Interaction and Understanding

Effectiveness Scores

- Applied Behavior Analysis: 2.00
- Floortime: 1.80
- Horse Therapy: 1.50
- Aquatherapy: 1.40
- Exercise: 1.30
- Speech Therapy: 1.20
- Gluten-Free and Casein-Free: 1.00
- Occupational Therapy: 0.90
- Music Therapy: 0.80
- Physical Therapy: 0.70
Best Treatments for **Stimming/ Perseveration/ Desire for Sameness**

**Effectiveness Scores**

- Applied Behavior Analysis
- Sensory Integration
- Floortime
- Occupational Therapy
- Diflucan
- Music Therapy
- Exercise
- Special Multivitamin for ASD
- Metronidazole
- Physical Therapy
Best Treatments for **Aggression/Agitation**

**Effectiveness Scores**

- Feingold Diet: 1.40
- Applied Behavior Analysis: 1.10
- Corn-free: 1.00
- Risperdal: 0.90
- Abilify: 0.80
- Essential oils: 0.70
- Exercise: 0.60
- Aquatherapy: 0.50
- Floortime: 0.40
- Lamictal: 0.30
Best Treatments for Anxiety

Effectiveness Scores

- Exercise
- Essential oils
- Feingold Diet
- Buspar
- Zoloft
- Aquatherapy
- Prozac
- Floortime
- Applied Behavior Analysis
- CeleXA
Best Treatments for Cognition

Effectiveness Scores

- Applied Behavior Analysis
- Floortime
- Feingold Diet
- Gluten-Free and Casein-Free
- Music Therapy
- Cod Liver Oil
- Exercise
- Gluten-Free
- Speech Therapy
- Injected Vitamin B12
Best Treatments for Constipation

Effectiveness Scores

- Miralax: 2.50
- Dulcolax: 2.40
- Magnesium Citrate: 2.30
- Colace: 2.00
- Digestive Enzymes: 1.40
- Probiotics: 1.00
- Vitamin C: 0.90
- Gluten-Free: 0.80
- Healthy Diet: 0.70
- Gluten-Free and Casein-Free: 0.60
Best Treatments for Diarrhea

Effectiveness Scores

- Corn-free
- Food-Avoidance (observation)
- Metronidazole
- Gluten-Free and Casein-Free
- Gluten-Free
- Healthy diet
- Probiotics
- Digestive Enzymes
- Saccharomyces boulardii
- Low-Sugar
Best Treatments for Hyperactivity

Effectiveness Scores

- Ritalin
- Exercise
- Aquatherapy
- Intuniv
- Essential oils
- Sensory Integration
- Focalin
- Floortime
- Adderall
- Horse Therapy
Best Treatments for Irritability

Effectiveness Scores

Feingold Diet: 1.5
Food-Avoidance (observation): 0.8
Sensory Integration: 0.7
Essential oils: 0.6
Risperdal: 0.6
Exercise: 0.6
Corn-free: 0.6
Ability: 0.6
Magnesium Citrate: 0.6
Gluten-Free and Casein-Free: 0.6
Best Treatments for Lethargy

Effectiveness Scores

- Injected Vitamin B12
- Exercise
- Carnitine
- Fluconazole
- Food-Avoidance (observation)
- Nystatin
- CoQ10
- Special Multivitamin for ASD
- Gluten-Free and Casein-Free
- Diazepam
Best Treatments for Seizures

Effectiveness Scores

- Lamictal
- Tegretol
- Topamax
- Depakote
- Valium
- Feingold Diet
- Gluten-Free and Casein-Free
- Food-Avoidance
- Klonopin
- Lexapro
Best Treatments for **Self-Injury**

**Effectiveness Scores**

- Applied Behavior Analysis
- Gluten-Free and Casein-Free
- Food-Avoidance (observation)
- Exercise
- Buspar
- Feingold Diet
- Risperdal
- Specific Multivitamin for ASD
- Food-Avoidance (food testing)
- Horse Therapy
Best Treatments for Falling Asleep

Effectiveness Scores

- Melatonin: 2.3
- Valerian Root: 1.2
- Clonidine: 1.1
- Feingold Diet: 0.8
- Essential oils: 0.7
- 5-HTP: 0.6
- Exercise: 0.5
- Quetiapine: 0.4
- Diphenhydramine: 0.3
- Gluten-Free and Casein-Free: 0.2
Best Treatments for **Staying Asleep**

**Effectiveness Scores**

- Melatonin: 1.00
- Feingold Diet: 0.67
- Clonidine: 0.67
- Valerian Root: 0.67
- Exercise: 0.67
- Food-Avoidance (observation): 0.67
- Food-Avoidance (food testing): 0.67
- Gluten-Free and Casein-Free: 0.50
- Essential oils: 0.50
- Casein-Free: 0.50
Summary

What the results tell us so far:

• Medication benefit scores are, on average, slightly higher than their adverse scores while,
• Nutritional supplements, diets and therapies tend to have benefit scores that are much higher than their adverse scores.
• Some highly-ranked treatments have received little/no formal research, so we recommend more research on those

Future:

These are the preliminary results based on the first 700+ responses. Once the response rate reaches 1000 we will reanalyze the results and post them online
Share your story

GO TO OUR WEBSITE AND FILL OUT THE SURVEY YOURSELF

AUTISM.ASU.EDU
Thank you to all of the families that participated. Thank you to ARI for funding. Thanks to all the organizations that helped advertise the survey!


Net Benefit

Average Benefit

Adderall  Abilify  Strattera  Buspar

-0.5  0  0.5  1

Adderall  Abilify  Strattera  Buspar

1  2  3  4  5

Adderall  Abilify  Strattera  Buspar

1  1.5  2  2.5  3  3.5