

PARENT RATINGS OF BEHAVIORAL EFFECTS OF BIOMEDICAL INTERVENTIONS

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The parents of autistic children represent a vast and important reservoir of information on the benefits—and adverse effects—of the large variety of drugs and other interventions that have been tried with their children. Since 1967 the Autism Research Institute has been collecting parent ratings of the usefulness of the many interventions tried on their autistic children.

The following data have been collected from the more than 27,000 parents who have completed our questionnaires designed to collect such information. For the purposes of the present table, the parents responses on a six-point scale have been combined into three categories: “made worse” (ratings 1 and 2), “no effect” (ratings 3 and 4), and “made better” (ratings 5 and 6). The “Better:Worse” column gives the number of children who “Got Better” for each one who “Got Worse.”

DRUGS	Parent Ratings					DRUGS	Parent Ratings					DRUGS	Parent Ratings				
	Got Worse ^a	No Effect	Got Better	Better: Worse	No. of Cases ^b		Got Worse ^a	No Effect	Got Better	Better: Worse	No. of Cases ^b		Got Worse ^a	No Effect	Got Better	Better: Worse	No. of Cases ^b
Actos	19%	60%	21%	1.1:1	140	Dilantin ^d	28%	49%	23%	0.8:1	1127	Prolixin	30%	41%	28%	0.9:1	109
Aderall	43%	26%	31%	0.7:1	894	Behavior	28%	49%	23%	0.8:1	1127	Prozac	33%	32%	35%	1.1:1	1391
Amphetamine	47%	28%	25%	0.5:1	1355	Seizures	16%	37%	47%	3.0:1	454	Risperidal	21%	26%	54%	2.6:1	1216
Anafranil	32%	39%	29%	1.1:1	440	Fenfluramine	21%	52%	27%	1.3:1	483	Ritalin	45%	26%	29%	0.6:1	4256
Antibiotics	33%	50%	18%	0.5:1	2507	Haldol	38%	28%	34%	0.9:1	1222	Secretin					
Antifungal ^c						IVIG	7%	39%	54%	7.6:1	142	Intravenous	7%	50%	43%	6.4:1	597
Diflucan	5%	34%	62%	13:1	1214	Klonopin ^d						Transderm.	9%	56%	35%	3.9:1	257
Nystatin	5%	43%	52%	11:1	1969	Behavior	31%	40%	29%	0.9:1	270	Stelazine	29%	45%	26%	0.9:1	437
Atarax	26%	53%	21%	0.8:1	543	Seizures	29%	55%	16%	0.6:1	86	Steroids	34%	30%	36%	1.1:1	204
Benadryl	24%	50%	26%	1.1:1	3230	Lithium	22%	48%	31%	1.4:1	515	Tegretol ^d					
Beta Blocker	18%	51%	31%	1.7:1	306	Luxox	31%	37%	32%	1.0:1	251	Behavior	25%	45%	30%	1.2:1	1556
Bupar	29%	42%	28%	1.0:1	431	Melbaeri	29%	38%	33%	1.2:1	2108	Seizures	14%	33%	53%	3.8:1	872
Chloral Hydrate	42%	39%	19%	0.5:1	498	Mysoline ^d						Thorazine	36%	40%	24%	0.7:1	945
Clonidine	22%	32%	46%	2.1:1	1658	Behavior	41%	46%	13%	0.3:1	156	Tofranil	30%	38%	32%	1.1:1	785
Clozapine	38%	43%	19%	0.5:1	170	Seizures	21%	55%	24%	1.1:1	85	Valium	35%	42%	24%	0.7:1	895
Cogentin	20%	53%	27%	1.4:1	198	Naltrexone	18%	49%	33%	1.8:1	350	Valtrex	8%	42%	50%	6.7:1	238
Cylert	45%	35%	19%	0.4:1	634	Low Dose						Zarontin ^d					
Naltrexone						Naltrexone	11%	52%	38%	4.0:1	190	Behavior	34%	48%	18%	0.5:1	164
Dipakene ^d						Paxil	34%	32%	35%	1.0:1	471	Seizures	20%	55%	25%	1.2:1	125
Behavior	25%	44%	31%	1.2:1	1146	Elenorbath ^d						Zoloft	35%	33%	31%	0.9:1	579
Seizures	12%	33%	55%	4.6:1	781	Behavior	48%	37%	16%	0.3:1	1125						
Desipramine	34%	35%	32%	0.9:1	95	Seizures	18%	44%	38%	2.2:1	543						

BIOMEDICAL/ NON-DRUG/ SUPPLEMENTS	Parent Ratings					BIOMEDICAL/ NON-DRUG/ SUPPLEMENTS	Parent Ratings				
	Got Worse ^a	No Effect	Got Better	Better: Worse	No. of Cases ^b		Got Worse ^a	No Effect	Got Better	Better: Worse	No. of Cases ^b
Calcium ^e	3%	60%	36%	11:1	2832	Transfer Factor	8%	47%	45%	5.9:1	274
Cod Liver Oil	4%	41%	55%	14:1	2550	Vitamin A	3%	54%	44%	16:1	1535
Cod Liver Oil with						Vitamin B3	4%	51%	45%	10:1	1192
Bethanecol	11%	53%	36%	3.4:1	203	Vit. B6/Mag.	4%	46%	49%	11:1	7256
Colostrum	6%	56%	38%	6.8:1	851	Vitamin C	2%	52%	46%	20:1	3077
Detox. (Chelation) ^c	3%	23%	74%	24:1	1382	Zinc	2%	44%	54%	24:1	2738
Digestive Enzymes	3%	35%	62%	19:1	2350	SPECIAL DIETS					
DMG	8%	50%	42%	5.3:1	6363	Candida Diet	3%	39%	58%	21:1	1141
Fatty Acids	2%	39%	59%	31:1	1680	Feingold Diet	2%	40%	58%	26:1	1041
5-HTP	11%	42%	47%	4.2:1	644	Gluten-/Casein-Free Diet	3%	28%	69%	24:1	3593
Folic Acid	5%	50%	45%	10:1	2505	Low Oxalate Diet	7%	43%	50%	6.8:1	164
Food Allergy Trtmt	2%	31%	67%	27:1	1294	Removed					
Hyperbaric Oxygen Therapy	5%	30%	65%	12:1	219	Chocolate	2%	46%	52%	28:1	2264
Magnesium	6%	65%	29%	4.6:1	301	Removed Eggs	2%	53%	45%	20:1	1658
Melatonin	8%	26%	66%	8.3:1	1687	Removed Milk					
Methyl B12 (nasal)	10%	45%	44%	4.2:1	240	Products/Dairy	2%	44%	55%	32:1	6950
Methyl B12 (subcut.)	6%	22%	72%	12:1	899	Removed Sugar	2%	46%	52%	27:1	4589
MT Promoter	8%	47%	44%	5.5:1	99	Removed Wheat	2%	43%	55%	30:1	4340
PSP (Vit. B6)	11%	40%	48%	4.3:1	920	Rotation Diet	2%	43%	55%	23:1	1097
Pepcid	11%	57%	32%	2.9:1	220	Specific Carbo-hydrate Diet	7%	22%	71%	10:1	537
SAMe	16%	62%	23%	1.4:1	244						
St. Johns Wort	19%	64%	18%	0.9:1	217						
TMG	16%	43%	41%	2.6:1	1132						

- A. “Worse” refers only to worse behavior. Drugs, but not nutrients, typically also cause physical problems if used long-term.
 B. No. of cases is cumulative over several decades, so does not reflect current usage levels (e.g., Haldol is now seldom used).
 C. Antifungal drugs and chelation are used selectively, where evidence indicates they are needed.
 D. Seizure drugs: top line behavior effects, bottom line effects on seizures
 E. Calcium effects are not due to dairy-free diet; statistics are similar for milk drinkers and non-milk drinkers.

The dosage below should be adjusted up or down by bodyweight; ie, half for a 30-lb child, and double for 120 pounds and above.

The following recommendations are based on the results of a published study that measured the effect of a multi-vitamin/mineral supplement on children with autism.

Adams JB et al., Effect of a Vitamin/Mineral Supplement on Children with Autism, BMC Pediatrics 2011, 11:111

The recommendations are similar to what was used in the Adams et al 2011 study, but slightly modified based on the results of that study. We recommend starting at a low dose, and gradually increasing over several weeks – some individuals may be better with half or ¾ dose.

VITAMINS	Recommended Supplement (for 60 lb child)	RDA (4-8 yr)	Upper Limit
Vitamin A (as mixed carotenoids)	6000 IU carotenoids ^a (equivalent to 3000 IU Vit. A)	400 mcg (1333 IU)	900 mcg (3000 IU)
Vitamin C (ascorbic acid)	500 mg	25 mg	650 mg
Vitamin D	1000 IU (some individuals may need more, especially if little exposure to direct sunlight)	5 mcg (200 IU)	Children - 50 mcg (2000 IU) Teens/Adults – 100 mcg (4000 IU)
Vitamin E (including mixed tocopherols)	250 IU	7 mg (10.5 IU)	300 mg (450 IU)
Vitamin K	55 mcg	55 mg	ND
B1 (thiamin HCl)	30 mg	0.6 mg	ND
B2 (riboflavin)	40mg	0.6 mg	ND
B3 (niacin/niacinamide)	15 mg niacin 20 mg niacinamide	8 mg	15 mg
B5	25 mg	3 mg	ND
B6	40 mg ^b	0.6	40 mg
B12 (methylcobalamin or cyanocobalamin)	600 mcg	1.2 mcg	ND
Folic Acid	800 mcg of folinic acid or methyltetrahydrofolate (not folic acid, which is insufficient for children with autism)	200 mcg	400 mcg
Biotin (d-biotin)	300 mcg	12 mcg	ND
Choline	250 mg	250 mg	1000 mg
Inositol	100 mg	n/a	n/a
MINERALS			
Calcium	300 mg (may need more if on dairy-free diet)	800 mg	2500 mg
Chromium	70 mcg	15 mcg	ND
Copper	0-400 mcg ^c	440 mcg	3000 mcg
Iodine	100 mcg	90 mcg	300 mcg
Iron	0 ^d	10 mg	40 mg
Lithium	300 mcg ^e	n/a****	n/a
Magnesium	250 mg	130 mg	110 mg ^f
Manganese	0-1 mg ^g	1.5 mg	3 mg
Molybdenum	100 mcg	22 mcg	600 mcg
Phosphorus	0 (eat fruits & vegetables)	500 mg	3000 mg
Potassium	50 mg	1500 mg	n/a
Selenium	40 mcg	30 mcg	150 mcg

Sulfur (MSM)	500 mg; or, take Epsom Salt baths	n/a	n/a
Zinc	10-20 mg	5 mg	12 mg

- a) Carotenoids are only converted to vitamin A as needed, so this level is safe even though it is at the Tolerable Upper Limit
- b) Some children and adults may benefit from much higher dosages, see section on High Dose Vitamin B6.
- c) Some children with autism have slightly elevated copper, so either low or no supplementation is sufficient for most children with autism.
- d) Iron should be added on an individual basis only if serum ferritin tests reveal a need for iron, or for girls/women who are of menstruation age. Suggest 5-10 mg of iron chelate for 4 weeks, followed by half that dosage afterwards
- e) For magnesium, the UL is the amount for supplements and does not count food sources
- f) Estimated daily intake of lithium in food is 1900 mcg/day for adults.
- g) One study found that children with autism have slightly elevated manganese, so either low or no supplementation is sufficient for most children with autism.

Duration: Lifelong, although improving diet and healing gut may reduce the need for supplementation.

Safety Note: Most vitamins are water soluble, and excess amounts of them will be safely excreted in the urine. Some vitamins (vitamins A, D, E, K) are fat soluble, and excess amounts of those can build up in the body and cause toxicity if taken at high levels (above what we recommend) for a long time.

Excess amounts of minerals can cause problems, and the upper limits listed above should not be exceeded without consultation with a physician or nutritionist.

Start with a low dose (1/5 of that listed above), and gradually increase over 1 month.