

ECT in Autism: A Parental Perspective

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My family: me, my husband Andy, and our kids:
Jonah (17), Erika (15), Hilary (13), Aaron (9) and
Gretchen (9)

But our life wasn't always so happy . . .



- **Alternative therapies:** gluten and casein free diet, vitamins, Auditory Integration Training, hyperbaric oxygen treatments
- **Medications:** olanzapine, ziprasidone, risperidone, quetiapine, oxcarbamazepine, divalproex sodium, sertraline, riluzole, clonidine, guanfacine, clonazepam, alprazolam, mixed amphetamine salts, methylphenidate
- **Hospitalization:** Ten months inpatient on the Neurobehavioral Unit at the Kennedy Krieger Institute



No lasting
improvement

Precedent:

- At Kennedy Krieger, 11 treatment-refractory patients all experienced significant improvement with ECT.
- Since then, other respected hospitals have reported similar findings: Mt. Sinai in New York, University of Michigan, University of Mississippi, and La Pitié Salpêtrière in Paris.

Consoli A & Cohen J et al. (2013). Electroconvulsive therapy in adolescents with intellectual disability and severe self-injurious behavior and aggression: a retrospective study. *European Journal of Child and Adolescent Psychiatry*.

Haq AU & Ghaziuddin N. (2014). Maintenance electroconvulsive therapy for aggression and self-injurious behavior in two adolescents with autism and catatonia. *The Journal of Neuropsychiatry & Clinical Neurosciences*.

More benign side effect profile than psychotropics:

- Antipsychotics, the most common medication prescribed to treat aggression and self-injury, can cause sometimes permanent and occasionally fatal side effects, including akathisia, tardive dyskinesia, glaucoma and neuroleptic malignant syndrome.
- Over 200 kids died in the U.S. between 2000 and 2006 due to complications from antipsychotics; since it was first used on kids in the 1940s, no child has ever died from ECT.

Something new:

After trying almost 20 different medications, none of which stabilized Jonah over the long term, it seemed unlikely that slightly different formulations would help.

In March 2010, Jonah started ECT

- Aggression dropped by over 90% during the acute course, during which he received three treatments a week for three weeks.
- Very slowly, treatment intervals were increased to Jonah's current maintenance schedule of one treatment every nine or ten days.
- Six years later, Jonah's rages are gone. He still lives at home and enjoys all his favorite activities, like swimming, boating, and hiking. Two years ago, Jonah switched schools, moving for the first time from a more restrictive to a less restrictive environment.

No obvious side effects from Jonah's 250 ECT treatments

- No evidence of memory loss, although Jonah's limited verbal ability makes this hard to assess. His teachers have not noticed any impairment, or any difficulty with previously acquired material.
- Jonah's academic performance dramatically improved after ECT, once his mood stabilized and he was able to focus on his schoolwork. Before ECT, Jonah learned an average of 7 new skills per month. In December 2010, he mastered 52 new skills.
- ECT is not aversive to Jonah: he never complains about going, and fully cooperates with IV placement. He recovers so quickly from treatment that he is able to go to school immediately afterward.



Jonah is not alone.

Mazurek et al (2013) reported that 53% of autistic children exhibit aggressive behaviors.

Not all are serious enough to require medical intervention, but many are: in the U.S., there are 9 specialized inpatient units that treat only developmentally disabled children and adolescents with dangerous behaviors.



So why isn't ECT used more frequently in this patient population?

- Legal restrictions
- Inaccessibility
- Unwillingness on the part of ECT providers
- Lack of knowledge on the part of child psychiatrists and developmental pediatricians





Aggression and self-injury are **treatable**.

This is Jonah and his dad on a cruise my family took in April 2014, something we never could have done before ECT.



It's important to note, however, that **ECT is not a cure for autism.**

EACH DAY I LIKE IT BETTER



AMY S. F. LUTZ

each day i like it better

AUTISM, ECT, AND THE TREATMENT OF
OUR MOST IMPAIRED CHILDREN

FOREWORD BY DIRK DHOSSCHE, MD,
AND CHARLES KELLNER, MD

My book about our experience with ECT, as well as those of six other families, was published by Vanderbilt University Press in April 2014.

It summarizes the most recent research on the safety and efficacy of ECT in the pediatric population in general and in developmentally disabled children and adolescents in particular.