

Please Don't Take Away My Autistic Son's Treatment

By Paul E. Peterson

Though they have never met my son David and have no information about his specific diagnosis or care, bureaucrats at the Food and Drug Administration are endangering his life by proposing to stop the one treatment that has allowed him to lead a happy life that includes learning, socializing and having loving relationships with his family.

David is one of a small percentage of individuals with autism and mental disabilities who engages in life-threatening self-injurious behaviors, including showing his hands down his throat and banging his head with such force as to permanently damage his ear. For the past 10 years he has been dissuaded from such activity by means of an abundance of rewards if he controls his self-harming behavior and an unpleasant, but harmless, two-second skin shock via an electronic stimulus device, or ESD, if he attempts self-injury.

While the device has been used effectively for many years with individuals like David at the Judge Rotenberg Educational Center, a residential special-needs school in Canton, Mass.,

the FDA is trying to ban it at the best of ideologically driven advocacy groups such as the Disability Law Center in Massachusetts, whose executive director calls the therapy "horrible torture."

Amazingly, the FDA says similar therapy is allowable if it is used to deter cigarette smoking. Denial to my son is justified on the grounds that he doesn't have the same ability as smokers to decide whether or not to receive aversive treatment. But that specious argument could be used to ban all medical treatments for people with intellectual disabilities for any condition whatsoever. It is standard practice to give people like David the same treatment others would receive as long as the consent of parents or guardians is obtained. As a further protection, all ESD treatments at David's school must be approved by a probate judge.

Further, David receives an abundance of rewards for controlling his behavior, and he is under the constant supervision of a dedicated, caring team. Denying treatment to people with disabilities when it is available to others violates the equal protection clause of the 14th Amendment. In its

1997 ruling in *Judge Rotenberg Educational Center Inc. v. Commissioner of the Department of Mental Retardation*, the Massachusetts Supreme Judicial Court unanimously affirmed a lower-court finding of contempt against the Commonwealth of Massachusetts for its interference with the use of electronic stimulus devices. The FDA's proposal ignores that decision.

The FDA might ban the harmless skin shocks that keep him from self-injury, though they have worked.

The FDA claims that alternative treatments are available. It is wrong. After trying many other institutions and therapies, including the drugs Mellaril, Thorazine, Haldol, Ritalin and Noctec, David in 1988 entered the highly regarded Neurobehavioral Unit at the Kennedy Krieger Institute that specializes in the treatment of self-injurious behaviors. Specialists explored a wide variety of treatment

protocols, including various drug therapies. After four months, the center's experts, finding no effective alternative, agreed that placement at the Judge Rotenberg Educational Center was the best available option for David. Our local school district authorized the placement.

The FDA asserts that skin shocks are no longer necessary but it provides no documentation that drugs are effective for people like my son. In the past, drug therapy aggravated David's self-injurious behavior. The use of psychotropic drugs also poses multiple risks of physical and psychological side effects. By contrast, skin shocks have no demonstrated side effects beyond a temporary redness to the skin that usually disappears within minutes.

The FDA also asserts that the skin shock constitutes physical and psychological harm. My wife and I have both experienced an ESD application. The experience is disagreeable, but not nearly as painful as a paper cut to the finger. Nor have we detected any sign of psychological damage to our son. Quite the contrary: David loves to visit his family, and he is no less happy to return to his friends in

the residence where he lives. Before arriving at his special-needs school, David's attempts at self-injury were continuous unless he was physically restrained. Today, he is in excellent physical health, and he has made striking gains in his social ability, curiosity and ability to carry out basic self-care. He participates in community events and visits his family about once a month. His attempts at self-injury average once a week, a low level he has sustained for the past several years.

Our son, who is now 45 years old, is enjoying a quality of life that my wife and I did not believe was possible before he had access to this treatment. The FDA's proposal would place his health—and life—at risk. The alternative treatment plan for him is physical restraints and mind-numbing drugs. For the sake of our son and others like him who have benefited from an electronic stimulus device, the FDA must withdraw its proposed regulation.

Mr. Peterson is a professor of government at Harvard University where he directs the Program on Education Policy and Governance.

After Fleeing the Nazis, a Legacy That Won't Run Dry

By Seth M. Stegel

How does one overcome almost unimaginable horror and trauma? For Holocaust survivors Howard and Lottie Marcus, the healing came, in part, from the hope that they could help to provide refuge for other Jews who might find themselves at risk. But after restarting their broken lives in America, this modest couple could never have imagined that they would end up giving what is likely the largest single charitable gift in Israel's history—\$400 million—to be announced June 24.

Howard and Lottie were born in pre-Hitler Germany—he in 1909, she in 1916. But they met in America. With the rise of Nazism, both had the

17-year-old Lottie persuaded her parents to allow her to go to the U.S.

Lottie's future husband was, by all accounts, a gifted dentist. After the election of Hitler in 1933, Howard made his way to Naples and a professional life there, only to find himself in jeopardy again in 1936, when Mussolini agreed to Hitler's demand that Italy expel all foreign Jews. As luck would have it, one of Howard's patients was the U.S. consul general and, in an act of kindness, the official broke U.S. law by backdating the visa request to a period when transit papers were still available.

Arriving in America, Lottie spoke fluent German, French and English, and she developed secretarial skills in all three languages. The harbor

his junior—declined. Even so, the friendship endured until Graham's death in 1976.

When Howard got to the U.S. in 1939, he had to redo years of his dental training to qualify for a license. Shortly after he opened his New York-based practice, he met Lottie at a dinner party and soon fell in love with her. He pursued her until she agreed to marry him. It was a small and bittersweet wedding. Other than the bride and groom and one of his three sisters, every member of the two families had perished in the Holocaust.

The Marcuses lived quietly and frugally. Their small indulgences included an occasional ski vacation (with Ben Graham and his girlfriend and future wife). One day, they asked their friend for investment advice

jobs, increase wages, and grow American businesses.

And because "Made in America" products and services currently face

With annual compounding, that investment grew to millions and then to many millions. But the Marcuses continued to live modestly. No one who knew them had any idea of the magnitude of their wealth.

The frugal couple bumped into young Warren Buffett. Now they've left millions to Israeli water research.

In the late 1970s, they followed the advice of Howard's doctor and moved from New York to the warmer climate of San Diego. In retirement they pursued their interest in world affairs

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That Won't Run Dry

desert farming, among other areas. A few years later they made a generous gift to support the school's Zuckerberg Institute for Water Research. But they still needed to find a home for the rest of their large, and growing, fortune.

In 2005 Howard and Lottie, now 95 and 89, made the long flight—in coach—from California to Israel. They returned with clarity on what to do with their estate.

Howard and Lottie loved America and often expressed gratitude for having been saved from certain death by the benevolence of their adoptive homeland. Yet they also often told friends that if Germany—"the most civilized nation in the world," in their words—could descend into barbarity and the mass murder of Jews

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