

Medical debate: Should autism block a man from getting a heart transplant?

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Twenty-three-year-old Paul Corby has a bad heart and a flawed mind.

The question before doctors now is whether his mental problems - he has a form of [autism](#) - are severe enough to make him a bad candidate for a [heart transplant](#).

Doctors at the Hospital of the University of Pennsylvania have said they are, according to Paul's mother, Karen. She disagrees and is using an online petition and the support of a network of autism advocates to make her case. Karen Corby says she was "stunned" by Penn's decision, then inspired by another family's successful fight with Children's Hospital of Philadelphia over a similar decision.

"I guess they thought we would accept it and just wait for the inevitable," said Corby, of Pottsville, Pa. She said she has not been told how long her son, who has a heart condition called left ventricular noncompaction, might live without a transplant.

Paul Corby initially took the decision well, but has since grown so depressed that his mother worries about how he'd react to another rejection.

"At first he was OK with it because he thought, 'At least I don't have to go through that surgery,'" his mother said, "and then he thought, 'Why not? Why don't they like me?'"

Paul Corby's situation is a window into the complex decisions that patients and doctors face when [vital organs](#) begin to fail. [Organ transplantation](#) is one of the few areas of [modern medicine](#) with overt and unavoidable rationing. There simply are not enough donated organs to go around, so doctors must make life-and-death choices. Nationally, 331 people died while waiting for heart transplants last year.

Karen Corby released a letter she received from Penn [cardiologist](#) Susan Brozena in June 2011. In it, Brozena said that she recommended against Paul Corby's getting a transplant "given his [psychiatric issues](#), autism, the complexity of the process, multiple procedures and the unknown and unpredictable effect of steroids on behavior."

Corby said her son - who is diagnosed with Pervasive Developmental Disorder Not Otherwise Specified - is high functioning and spends his days playing video games and writing the sequel to his pre-teen, self-published novel, Isaac the Runner. He carried his ever-present Princess Peach doll with him to his transplant evaluation. He takes medicine for an unspecified mood disorder, his mother said. He has shouted loudly enough that police have been called "three or four times" to the family's home.

Citing privacy rules, the Penn health system said it could not comment on Paul Corby's case. It released a written statement that said the transplant program reviews "all aspects" of a patient's condition, including his health status and post-transplant prognosis, and other health problems that could affect transplant success along with the interaction of drugs he takes and those he'll need after the transplant.

"Our criteria for listing an individual for transplant are regularly reviewed in comparison with national standards, but we always encourage patients to seek another opinion."

After Karen Corby said she was willing to give permission for Penn to discuss her son's case, health system spokeswoman Susan Phillips said that "the physicians involved believe that any discussion of the specifics of his case would be most unkind to him and therefore will not comment."

Phillips said Penn's transplant team has performed at least one other heart transplant in an individual with autism.

Thirty-eight percent of patients evaluated for heart transplants during the last two years there were told no, mostly because of other medical conditions that would affect their survival or quality of life after a transplant, Phillips said.

Karen Corby decided to start a petition on the website change.org after reading in January about 3-year-old Amelia Rivera, who was denied a kidney transplant at Children's because she was "mentally retarded." Her family's petition led to an outpouring of support. The hospital apologized and Rivera's family now says she has been cleared for transplant.

Corby's petition drew only about 4,000 signatures until Joslyn Gray, a freelance writer from Drexel Hill who has two children with Asperger's disorder, also part of the autism spectrum, wrote about Paul on the Babble.com website last week. The count had climbed to about 10,700 Monday.

Gray sees an issue that can only get bigger as more children with autism get older.

While autism was just one of the reasons listed for denying Paul Corby a transplant, Gray said she was "extremely disturbed that autism in and of itself was listed as an exclusionary factor."

With help from other parents, Karen Corby has now contacted the Mayo Clinic and two hospitals in Pittsburgh about putting Paul on their lists.

Transplant patients often face a difficult recovery and are on a complex drug regimen for the rest of their lives. The experience of being rescued from death by someone else's death is challenging emotionally even for people who go into the experience with superior social skills.

Robert Weinrieb, a psychiatrist who specializes in working with transplant patients at the Hospital of the University of Pennsylvania, said patients were rarely turned down for psychosocial reasons. People who are actively addicted to drugs or alcohol are excluded. In cases of serious psychiatric or cognitive problems, doctors want to know that patients have enough support from family members to manage their medications. Doctors don't want to have to sedate patients to perform minor procedures. To make the best use of organs, patients must be willing participants in rehabilitation.

Weinrieb, who has not met Paul Corby, said the social skills deficiencies common in autism can be a problem if patients need a long hospitalization.

Steroids, which are given in high doses after transplants, greatly magnify emotions. Weinrieb likened it to drinking 20 to 30 cups of coffee. Someone who already has trouble with anger or impulsiveness is "virtually guaranteed" to get worse on the drug, he said.

Daniel L. Coury, professor of pediatrics and psychiatry at Ohio State University and medical director for the Autism Speaks Autism Treatment Network, said it's hard to predict who will have a hard time with steroids.

People with autism have trouble with verbal and nonverbal

communication and with transitions. They often have limited interests, Coury said. Those characteristics can make them challenging patients, but there are ways to help them through difficult medical procedures. He said he had not heard anything about Corby that would disqualify him from a transplant. "To deny him outright doesn't sound quite appropriate to me," he said.

Karen Corby said her son is already on 19 medications, most for his heart condition. Although he always has someone with him, he takes the medicines by himself. He struggles with anxiety and has night terrors. He's a loner. He has not been diagnosed with specific mood disorder, she said, but takes a mood stabilizer. He's been more depressed and upset since Penn said no.

His heart problems make him breathless when he climbs stairs. He has to sleep practically sitting up. His father died of a stroke at 27 - Corby doesn't know if he had the same heart problem - and she fears for Paul.

He spends a lot of time working on his second book. The first was about a group of kids on a quest. It's not great literature, but it reveals an active mind. In the third chapter, the hero Isaac tells his mother he's embarking on a quest. "Do you mind if I go out for adventure?" he asks. "Rick's candy has been stolen from an evil ogre robot Chris Jerky."

During a visit last week, Paul answered questions with short, simple sentences, mostly averting his eyes. He is a pudgy young man with freckles and an auburn beard. There was no hint of emotion in his face even when he described strong feelings.

He said he worries about going out sometimes. "I feel like I might get nervous, and I might act out in public." Asked how he acts out, he said, "I push people. I break things." His mother said medication helps with that.

Autism, he said, has made him creative. He still feels "desperate" for a transplant. He's tired of being tired all the time and he's not scared of the surgery or a long stay in the hospital.

"I don't care how long I'm in there," Paul Corby said. "I just want my life to be saved. That's all."

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