

I am Josh

I am Josh. I was born on the day I was due, December 13, 1992 – and a little bruise I was, said the nurses. I was a robust 8 pounds 11 ounces, chunky and muscular. I breastfed well and thrived.



After 6 weeks, I went on the bottle. I was such a happy baby, always smiling and very content, says Mum. I played peek-a-boo and pat-a-cake with Brother. Everybody gave me cuddles and I gave them back.



I sat at 6 months old. I walked at 11 months old and weighed 25 pounds. I could say “Mama,” “Dada,” “ta” [thank you], “gone,” “juice,” and “bye.” I love bath time! I splash and play with my brother and the bath toys.

I am a strapping lad!



It's January 1994; I'm 13 months old. Off to the doctor for my MMR! Tonight I have a high fever. I don't feel so well in the morning, with severe diarrhea leaking through my clothes and onto my bedding. My stool is bright yellow, runny, and then like oxtail soup. Can you imagine? This went on for 5 days, and then I stopped “going” so much . . . Mum says “constipated.” I used to poop every day before the MMR, sometimes twice a day.

I'm so sorry, Mum, I don't know what is happening. I am miserable and upset. I'm sorry that I scream and cry and nobody can figure out why. Please don't pick me up, please don't cuddle me – I can't stand it! I don't like being touched anymore.

Mum says that changing my diaper became a nightmare with my screams. Brother says I'm withdrawn and will no longer play with him, asking, “Mummy why won't Josh play with me anymore, doesn't he like me? He won't even look at me.”



My family wondered, “How could our little boy have changed so quickly within four weeks of having the MMR vaccine?”

I am Josh. I am obsessed with light switches, climbing on chairs and tables to get to them, turning the light on and off. It is the same with door handles and opening and closing doors. I engage in repetitive behavior. I hate eye contact and ignore the cameras that I used to “ham it up” for.

I am scared to go outdoors, screaming when Mum puts on her coat. I tantrum and become a prisoner in my own home. But I am a prisoner in my own body. I am Josh.

I'm about 15 months old. Six weeks since my MMR vaccine, and I haven't verbalized a bit of language for at least 2 weeks. I'm not even trying. I used to sit on the potty, but I don't seem to remember what it is for. I used to sleep well, sleeping through the night from 6 weeks old. Now I don't.

I am Josh at 18 months old. I have poor behavior, poor interaction, little eye contact and a total loss of speech. I am only pooping once a week. I stand and spin and spin and flap my hands. My appetite is poor; I'm a picky eater – I eat the plastic wrapper instead of the food. I'm 2 years old now. I have feverish episodes, and I cannot tolerate lights. I have

Top right: Happy baby!

Top left: I am a strapping lad!

Above: Heather Edwards

Right: Josh on the potty 2 weeks before the MMR.

Opposite page: Josh at 27 months old – it was hard for the photographer to get him to look at the camera.

a hearing loss, and they've written in my chart, "Unspecified Meningitis." My fun is to bang doors shut, a cruel allegory of my life. Am I Josh?

I am Josh's mum Heather.

I accepted the reassurance of doctors that Josh's problems did not have anything to do with his first MMR vaccine . . . "a coincidence of timing," they said. How many mothers have heard that? At 3 years 9 months, I took him for the MMR booster. Josh immediately developed diarrhea, just as he did after the first MMR vaccination. Although the diarrhea only lasted 3 days, Josh's constipation became much worse. Soon, Josh was only moving his bowels twice a month; surely this could not be a coincidence. For Josh to develop diarrhea and regression once perhaps, but twice – surely not.

Josh's behavior regressed even worse. He engaged in constant screaming. Any toileting skills he'd gained went backwards. Two months after Josh received the MMR booster, I needed to put him back in diapers for wetting and frequent soiling. He was going through 7-8 pairs of pants a day and making his little bottom very sore.

Josh became more obsessive. I couldn't switch the position of knick knacks in the house. He would tantrum if the car didn't go in the direction he expected.

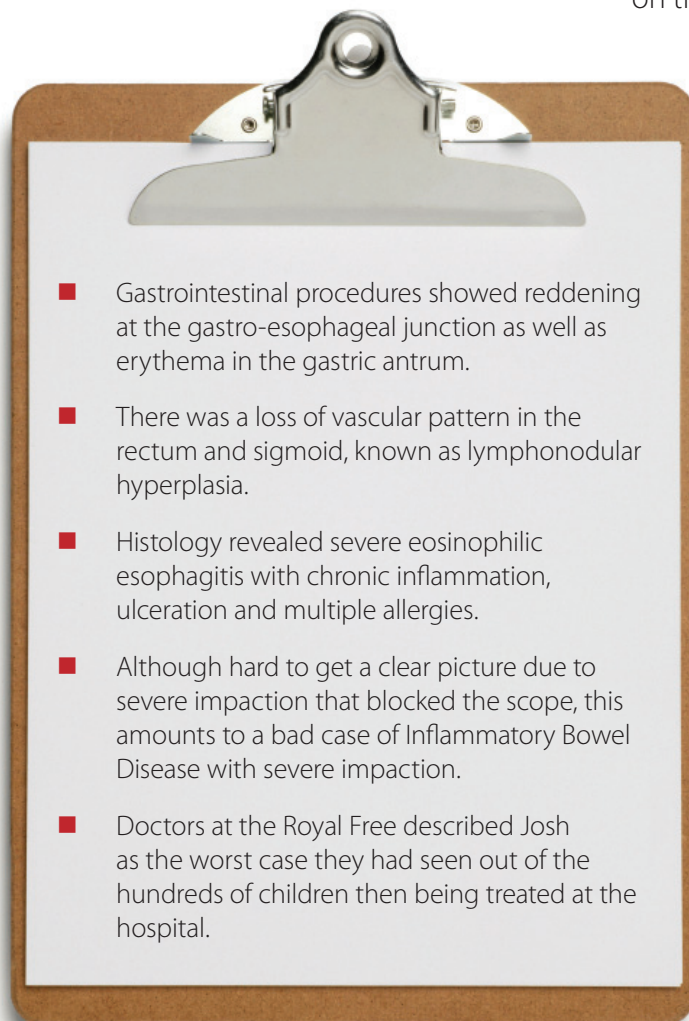
Josh was diagnosed with autism at 4½ years old. I cried for days.

I am Josh. I am nearly 6 years old. I chew objects that aren't food. I only move my bowels twice per month. I've only pooped three times in two years without the use of enemas.

And now I am 8. Finally some doctors have looked inside of me. There is inflammation in my duodenum, terminal ileum and colon. I'm not a strapping young lad. I am scrawny, pale, and underweight. My mum asks, "Where has our chunky little boy gone – our little sumo wrestler?" The hospital doesn't know what to do with me. I continue to need regular enemas and have persistent vomiting. Mum has asked for a referral to the Royal Free Hospital. (See "clipboard.")

Heather here again. When Josh was 10 years old, after a long series of manual evacuations, a tube was inserted directly into Josh's colon through his stomach into the abdominal wall to administer bottles of enema and sodium chloride to prevent impactions. The tubes kept getting lost, the enemas were making him sick, and we needed to resume enemas in his bottom, which caused bleeding.

After many more clearings for impaction, a medical consultant recommended removal of Josh's large bowel. But the surgeon only approved removal of the sigmoid colon. Josh now had a bowel bag. One evening, two weeks after coming



- Gastrointestinal procedures showed reddening at the gastro-esophageal junction as well as erythema in the gastric antrum.
- There was a loss of vascular pattern in the rectum and sigmoid, known as lymphonodular hyperplasia.
- Histology revealed severe eosinophilic esophagitis with chronic inflammation, ulceration and multiple allergies.
- Although hard to get a clear picture due to severe impaction that blocked the scope, this amounts to a bad case of Inflammatory Bowel Disease with severe impaction.
- Doctors at the Royal Free described Josh as the worst case they had seen out of the hundreds of children then being treated at the hospital.

out of the hospital, Josh seemed to be in some pain and was holding his tummy. There was an awful smell: his T-shirt was covered in blood. Josh's bag was full of blood. The doctor whom we called panicked and said that Josh needed to be admitted to the hospital immediately. The most likely cause was attributed to a knot in the scarring tissue inside his abdomen.

Josh still had stretches with no stool output into the bag; so laxatives continued, but they did not help.

One Saturday morning when Josh was 11, he was screaming in the bathroom trying to remove his bowel bag; he vomited all over me as I removed it. A huge hard stool was stuck in his abdominal opening as he vomited on me again. Josh had another X-ray showing impaction, resulting in the medical consultant recommending that Josh's entire colon be removed.

Surgery was booked for September 2004. The surgeon was unsure as to what procedure would be done, needing to decide once he had looked inside of Josh on the operating table. A staff member came from the operating room to me and said, "I'm afraid we have had to remove the whole of Josh's colon." It was so badly diseased. Josh would now have a terminal ileostomy bag; the



“ For Josh to develop diarrhea and regression once perhaps, but twice – surely not. ”

- on the spectrum

“ The colon sample was later found at the other end of the lab on a workbench. It was now useless for research, having deteriorated badly. The colon had not been logged into the system and, therefore, did not need to be logged out. Whoever did this knew how important it was. We had lost an irreplaceable piece of evidence. ”



Above: This is how the school let Josh come home. How can I [Heather] trust anyone else to take care of Josh as well as I can?

output would never be formed, it would remain as a liquid.

Arrangements were then made to keep the entire colon for research. It was sent to the lab and frozen since the hospital could not get a hold of any dry ice to have it transported to Coventry Microbiology. Josh was in the recovery room vomiting from the anesthesia. He was moved to the Intensive Care Unit.

I checked that Josh's colon had been stored before we left the hospital, and I was told it was safe in the freezer of the immunology laboratory. In the coming days, I began arranging for a courier to collect the sample from the hospital. The hospital was called and told that a courier

would be able to collect the sample the next day, bringing dry ice and a suitable container. The hospital was instructed to ensure that the colon was able to be easily found in the freezer so that the courier didn't need to wait. The hospital was reassuring, saying the sample was in the freezer. You can imagine my shock when I received a phone call a few hours later informing me that, although the box had been found in the freezer, it was empty. The box was also clearly labeled with Dr. Wakefield's name and ready for the courier, although who wrote Dr. Wakefield's name was a mystery because it was supposed to go first to a different doctor at a laboratory.

This was very distressing to the immunologist, and he could not explain what had happened. The colon sample was later found at the other end of the lab on a workbench. It was now useless for research, having deteriorated badly. The colon had not been logged into the system and, therefore, did not need to be logged out. Whoever did this knew how important it was. We had lost an irreplaceable piece of evidence.

Hammersmith Primary Care Trust, which oversees Chelsea-Westminster Hospital, apologized. After a private internal investigation, the hospital claimed that there had most likely been a breakdown in communication. Then the hospital said they did not think that the colon had ever been put in the freezer: this was a change in their story – they evidently forgot they had already told us that the box had been found in the freezer empty. Josh had stayed in the hospital for almost 2 weeks following his operation and there was clearly no possibility that the colon could have remained on the lab benches unnoticed during this time, deteriorating like a piece of rotting meat. We were invited to look around the labs, and there was little security in place.

The Healthcare Commission and the Health Service Ombudsman each carried out a further



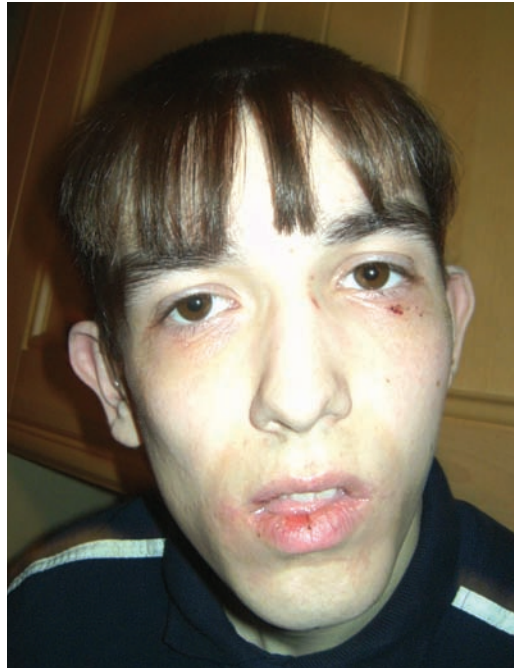
Left: Aaron, Josh, and Jodie. Right: Josh offering a kiss to Andy and Carmel Wakefield at GMC. Andy always says to Josh, "How's my boy?"

investigation. Tighter security is now in place, and all samples are now logged into the system. The story of Josh's missing and abused body part was later covered by Peter Hitchens in the *Mail on Sunday*, under the title "This boy's illness may be linked to the MMR, so who destroyed the crucial evidence?"

Josh's operation was having a huge impact on the whole family; it was like having a baby since he needed to keep being changed and having his bag emptied during the night. It was disturbing his brother Aaron's sleep. Josh needed his own bedroom, and so we had to buy a different house with a cumbersome mortgage. I have been changing Josh's bag twice per night for over 5 years. Sometimes there is stool "everywhere" and the bedding must be thoroughly changed. I have not had a full night's sleep. My beloved son looks as if he is a victim of a concentration camp. And the final blow – the vilification of Dr. Andrew Wakefield . . . who has stood by the children, who listened to the parents when others would not. An insult to Dr. Andrew Wakefield is an insult to my child. Josh and I went to hear the verdict at the GMC; when Dr. Wakefield was on the news that evening, Josh went up to the TV and touched his face on the screen. How my son loves him . . . My son knows the truth of what happened inside of him, and so do I.

What will be Josh's future? What will be the future of all children if men of integrity like Dr. Wakefield are not allowed to conduct objective scientific inquiry? Josh's own current medical consultant, who is a gastroenterologist, has confessed to me that he would rather be out of the country when Josh is admitted to the hospital for his ongoing medical problems because he "cannot move Josh forward."

I am Josh. I am 17 years old. I have not been able to eat any solid food – nothing but elemental formula for nearly 4 years. I am in pain and have tantrums. I have been found to have a mitochondrial dysfunction. I have chronic electrolyte abnormalities, with periods of rapid dehydration when my stoma output is double what it should be due to my ongoing bowel disease; Mum finds me licking salt because of this. I am scheduled to have a gastrostomy, which means I'll have a permanent feeding tube into the stomach. I cannot talk. My eyes become inflamed and my mouth ulcerates when my bowels flare up even more with increased stoma output – if you could possibly imagine it getting worse. I smack myself on the chest at school as if I am in pain . . . Mum thinks due to the lesions in my esophagus. And although I have become aggressive and am withdrawing more into myself, for fleeting moments I can give the cuddles and kisses that I remember before the MMR. When I was really Josh.



Above: Josh today: February 18, 2010.



Above: Josh at 16 years old.

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- on the spectrum

I am Aaron, now 19 years old and brother to Josh. When Mum showed me the photos that were going to be used for *The Autism File*, I was extremely angry and disgusted with her. "Mum you cannot allow pictures to be published of Josh looking like that." Now, having sat down and chatted to my mum on my own, I can now see where Mum is coming from.

To me, my mum is a diamond, and what she is having to cope with at the moment with Josh only our family knows. Mum is in and out of bed ALL night tending to Josh's ileostomy bag, the operation which was supposed to give my brother a better quality of life. I have always admired Mum for her strength to keep going. I now know that is a front for the rest of us. Mum broke down and cried to me; she told me how she is feeling guilty, that she is not doing enough to help Josh. Everything my mum ever does is to try and help Josh.

By telling Josh's story and showing the photos, maybe someone out there may be able to help my brother. As having spent 4 weeks in hospital stabilizing Josh, doctors still do not have the answers for us.

I long for my brother to be able to eat again. This year he will be 18 and won't be celebrating it like I did with a big party. There will be no first pint for Josh, how it should of been with me taking him down to the pub and to his first nightclub. Me his big brother looking out for him. Oh how jealous I used to be watching the relationships my friends had with their brothers.

I love Josh to bits and wish I could help relieve the pain and suffering he has to live with every day of his life. I am so proud of my parents and how they have pulled together when our family could so easily have fallen apart.

I am going to finish by asking that readers please, please don't judge my mum for this article and hope maybe help is out there somewhere.



Parents of children with ASD:*

- **4x** more likely to fear their child will not have enough financial support after the parents die.
- **More than 3x** more likely to fear that caring for a child will cause their own retirement shortfall.
- **More than 3x** more likely to say the cost of current care is draining their current financial resources
- **5x** more likely to say the cost of care will drain their future financial resources

*Easter Seals Living with Autism Study

YOUR CHILD MAY BE IN DANGER

You take great care of your child, **WHO** will take care of them when you're gone?

Are you concerned about **WHERE** the money will come from?

Do you know **HOW** to make the government a partner in your child's future care?

Do you have peace of mind about **WHAT** your child's future will be like?

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