

September 9, 2007

Quest for a miracle cure

These parents believe horses and shamans can unlock their son's autistic mind. This is their journey of discovery

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A child is born, and the child seems blessed. He lives in the richest nation on Earth, at a time of greater wealth and understanding than any in history. The infant even has interesting parents: one British, one American, each a little famous in their own right.

But then something disquieting happens. Perhaps this was your child, too.

He starts to go backwards. First he loses his language, then he enters a solitary hell. He turns away when touched and arches his back when held. He lines up his toys in rows, and seems afraid of things that should hold no fear. He appears not to notice you, and his indifference makes you feel snubbed.

Soon the real heartache starts. You see other children play together in a sandpit while yours is to one side, obsessively pouring and repouring sand through his fingers. Sudden firestorms run through his nervous system, making him scream in panic and pain. Later, in the calmer years when he is four or five, other children's attempts at friendship are rebuffed. This is not because your child wants no companions: the truth might be that he yearns for them. But he is mystified by social interaction, and conversation makes him nervous, as he has no idea how to respond. So he turns away with a distant expression, seeming cold and weird. This is autism. Your lovely offspring looks condemned to what, in 1943, Leo Kanner first described as "extreme autistic loneliness", and many readers of this magazine will know a family that is affected. In the UK, 1 in 100 children is on the autistic spectrum.

It is a mystifying disorder. But on a farm in Texas, a British father thinks he has found a way into the mind of his autistic son. The boy has learnt to talk thanks to his relationship with a horse. He can quell his tantrums, express his feelings, even do maths and spelling — all because of a horse. He is the Horse Boy, and the loss of his symptoms is a challenge to conventional thought on how to handle his condition.

Can you love a child out of autism? Can you at least save your child from its worst effects, without destroying your marriage and yourself? All parents long to be good parents. The question is: how? Can the answer possibly be a horse?

If any family is equipped to combat the mysteries of this agonising disorder, it is this one. Kristin Neff, the mother, is a developmental psychologist with easy access to other experts because they are on the same corridor at Texas University. Rupert Isaacson, the father, is a campaigning writer and former horse trainer whose life has been spent drawing attention to injustice. For the

past five years, their talents have been focused on Rowan, their autistic son. "You've got to put yourself inside his mind," says Rupert, who learnt patience and empathy in his earlier career as a horse whisperer, hired to bring manic animals under control.

To start with, Rowan seemed normal. He talked quite early, and at 12 months he had five words starting with B. Then he lost them. When he failed to pass certain milestones at 18 months, his mother knew something was up. But such are the misunderstandings around his condition that even she, an associate professor of human development, would joke that at least it wasn't autism, because he made such good eye contact. Only now does she appreciate that the clichés of autism are not supported by proper research. How many autistic children are as loving as this one? How many can look a parent straight in the eye? We don't know: the work has not been done.

Kristin asked an early childhood intervention team to assess her son. It offered no diagnosis, perhaps to delay the day when meeting his needs would dent its budget. In the end, she diagnosed him herself by looking up "early warning signs of autism" on the internet. He had every signal listed. For a condition in which early intervention is crucial, the family had lost six months.

We don't know what causes autism, although the interaction of genes with toxins is suspected. (Rowan lacks a gene to produce glutathione, an antioxidant that combats toxins; a report on the possible role of plastics and pharmaceuticals in autism is due next year.) At least we now understand what autism is. Put simply, the brain is wired differently. Scans suggest that the white matter in the frontal cortex, the brain's "computer cables", is overgrown. Instead of connecting all the parts of the brain, there might be a mass of cables leading to one area, so part of the brain has more wiring than it needs, while another part is poorly served. The only normal areas are the visual cortex and those at the back of the brain that store memories.

As a result, many autistic people don't think in words but in pictures, patterns or symbols. "When I read, I translate written words into colour movies or I simply store a photo of the written page to be read later," says Temple Grandin, one of those who, in the past 20 years, have opened up the autistic world to us by learning how to describe it in verbal language. We still don't know what life is like for those at the most afflicted end of the spectrum, but

it is likely that sights, sounds and touches mix together. "It must be like seeing the world through a kaleidoscope and trying to listen to a radio station that is jammed with static at the same time," says Grandin. That's not all. Some report a broken volume control that causes sounds — a speech therapist's voice, say — to jump erratically from a loud boom to inaudible, plus a nervous system in regular fear or panic.

The extra brain cabling gives a minority of autists dazzling "savant" skills, such as the ability of Kim Peek, who inspired the film *Rain Man*, to read two pages simultaneously, one with each eye, or that of Daniel Tammet, a maths genius in Kent, to recall pi to 22,514 decimal places. For others, ordinary experience is intolerable. They say they can hear the blood whooshing through their veins, or every sound in a school building. Fluorescent lighting can cause an entire room to pulsate on and off, 50 times a second. Meanwhile, missing wires can mean no flexibility or common sense. A child at a birthday party who is surrounded by peers licking ice cream may

stare at his cone in bewilderment because, although he loves ice cream, he has always eaten it with a spoon.

For Rowan, autism takes a form called PDD-NOS, which means his social and communication skills are severely impaired but he does not fit the classic definitions. He began to flap his arms and babble, and to retreat into himself for hours at a time. For two years he suffered neurological firestorms in which he would flail around on the ground. "It could be because a breath of wind touches his cheek, and it feels like he's being brushed with a flame-thrower," Rupert says.

"He can't communicate what's wrong." Looking through old notes, Rupert says he wondered if his son would ever be able to ask a question, or hold a parent's hand and go for a walk.

The diagnosis was in April 2004, when Rowan was 2½. His parents tried the usual prescription: speech and occupational therapy, applied behavioural analysis, chelation to get rid of toxins, supplements to adjust the child's chemistry this way or that. But there was a problem. Much of the evidence favours applied behavioural analysis, which uses strict routine and a system of rewards and subtle punishment to foster basic skills and inhibit unwanted behaviour. But this has been in vogue for a while, so nothing else has been tested to the same degree. And these parents, who live in the hippie belt near Austin in Texas — equivalent to Devon's Totnes or Yorkshire's Hebden Bridge — were always going to find it difficult.

Kristin is Buddhist, and Rupert, in the words of his friend Rian Malan, is open-hearted, optimistic "and vulnerable to enchantment". After meeting African healers to research *The Healing Land*, his book about the Kalahari Bushmen, he is open to communion with the spirit world. Strict routine is not their thing, and neither is pretending not to notice a child's distress ("ignoring negative behaviour" as therapists put it). Their instinct is to cuddle and reassure, and to put Rowan first. "We're his slaves," Rupert says. They also have an intellectual objection to the accepted wisdom. Life throws our children curve balls. Shouldn't we throw curve balls too? If structure helps autistic children in the short term, does it reinforce the rigidities of the disorder in the long term? When you start to think like this, of course, you are on your own. Then came an accidental discovery. Like many autistic boys, Rowan has energy; one day he escaped through a fence and got among a neighbour's horses. A quarter horse called Betsy started displaying submissive body language to the child. This was odd. Despite her gentle eyes, Betsy is a grumpy alpha-mare who would not think twice about putting two hooves in the face of a horse that annoyed her, or taking an incompetent rider straight back to the barn.

Yet here she was with her head on the ground, submitting to a babbling two-year-old boy. For years, Rupert had been a professional horse trainer, and his first reaction was to cry. Here was evidence that his son might share his passionate connection with horses. But if autism gave Rowan an eerie direct line to the horse, it also meant he could not learn to ride. He had little control over his body, and if distracted he would fall off. As father and son, they could take this no further. Rupert broke down.

Then came a second chance event. Commissioned to write an article on Honduras, Rupert went into the hills — and came across all these dads on horseback with their children. He could teach Rowan to ride after all, he realised: they could share the same horse. On his return, he put a

saddle on Betsy and said to Rowan: Do you want to get up? And the boy gave him a direct answer for the first time. "Up! Up!" he said, and suddenly this father-son experiment was not about learning to ride. It was about finding a route into the mind of an autistic child.

As they went riding in the days that followed, they talked. The father said: Do you want to go fast or slow? Do you want to go to the water or do you want to go to the trees? Oh look, a crow! A crow is black. How do you spell crow? Give Betsy a hug. Thank you, Betsy! And Rowan responded. In place of his usual babble and empty repetitions were some meaningful words. At first the new skill came only on the horse, vanishing like a dream when he was on the ground. Then it extended into his wider world, too. After six months, when Rowan was 3½, he could tell Betsy spontaneously that he loved her. "We really owe the bulk of Rowan's cognitive speech to Betsy," says Rupert today. "I've never been as grateful to a living being as I am to that horse."

Just as significant was the effect on Rowan's tantrums. He was still having firestorms — the screaming, the writhing, the passers-by asking to call an ambulance. But although he might be a jerking ball of random energy until being put in the saddle, and spasm again as soon as he got off, on Betsy he was calm.

He had also responded to healers. Just after the diagnosis, Rupert brought a party of African hunter-gatherers to America to publicise the loss of their land to diamond mining. The bushmen became part of a 10-day event in California, and some took Rowan into their ceremonies, praying over him and going into trance. His symptoms seemed to reverse: he even showed people his toys. Afterwards, he regressed. But not as far back as before.

By now speech therapists were giving up on Rowan: he could talk either on Betsy or off her, but not with therapists — not in their closed rooms. The professionals were saying that they could help no further. What did seem to work was a grumpy horse and an encounter with an ancient culture. Like any good writer, Rupert decided to take his discoveries to an extreme. Where in the world, he wondered, do horses and healers combine?

We are in a landscape that could be Montana in the United States, or Britain's north Pennines. The light is shifting in that magical way all Britons take for granted, as the sun diffuses through cloud and rain. This is not Britain; it's Mongolia. There are eight of us with Rowan: his parents, a guide, a writer and a photographer for this magazine, and a small film crew. The child is in distress again. He is refusing to go near a horse.

Two days earlier he has been subjected to what looks to an outsider like child abuse. He has been whipped by a shaman — an intermediary between the natural and spirit worlds — and force-fed milk, then held under a noisy drum. He recovered to become peaceful, sociable, even giggly. But the refusal to go near a horse is deeply inconvenient.

If you go to www.horseboymovie.com, you will find a version of this story, as told by Rupert. He explains that Mongolia is where the horse evolved and humankind learnt to ride, and where the word shaman, meaning "he who knows", originates. So Rupert's idea is to ride with Rowan on horseback from healer to healer in Mongolia, and to wash him in sacred waters. The journey is to end in one of the most remote regions on Earth, where the shamans are particularly powerful.

The website does not report that Kristin thought the plan was mad. She went along with it on a "Yes, dear" basis, believing it would never happen. Not only did it happen, but publishers have bought the unwritten book of this trip for sums so high that in some countries it has broken records. There is to be a film, *The Horse Boy*, and Viking Penguin, the British publisher, is already excited about the "online viral marketing of the story" and trailers on YouTube and MySpace. Eighteen countries will publish the book, even if eastern Europe was not that interested and an editor claimed that in Greece there is no autism. That means they are hidden away in institutions, says Rupert, instantly determined to start a campaign there.

And so we find ourselves on the Mongolian steppe, among nomads who have never hosted tourists, ready to mount the half-wild horses they have lassoed for our journey. Until now Rowan has never spent more than three hours on horseback, but this trip is to last days. His parents express their hopes. Kristin's secret wish is that one day he'll find a charming woman who will let him live in eccentricity, as it's hard to imagine him independent — although easy to think of him making a living with animals. Rupert would love him to tell a lie, revealing a leap in his faculties. For now, each parent has the same desire: he is five and not potty-trained. If the shamans can get him to use a toilet, that would justify everything.

The venture is not as unhinged as it sounds. After being with Rupert for 12 years, Kristin is coming to trust his judgment; sure enough, it turns out there is a theoretical basis for Rowan's breakthroughs on horseback. The rocking motion, and the constant finding and refinding of balance, is thought to stimulate new brain connections. Leading researchers into autism are following this journey with interest. But the case for these parents is best made by their son. He's a sweet child, tactile and affectionate, and he is not hard to know. When upset he has the endearing, autistic habit of pulling words out of his memory that might correspond with what he feels, but not with what he's trying to say. So he'll scream "giraffe!" at the top of his lungs, or "immigration!" or "Smith!", the name of his old teacher, Miss Smith, when actually he wants to convey that he's anxious, or has lost a favourite toy. It takes just a day from meeting him to get him giggling in a game. Most impressive of all is his interest in the world — the opposite of the classic idea of autism.

But he's not giggling now. In fact, the trip starts badly and gets worse. The horses are fit and responsive. But Rowan is nowhere near one. For the first few days, most of the party travels on horseback while the boy, tired and upset, spends his time in the 4x4 support van. Soon his father contemplates having to change the book to *The Van Boy*. Days later, Rowan is still circumspect about horses: he has come to see them as something his father wants him to do.

Rupert is close to despair. Is he doing this for Rowan or himself? It is a question he has been asking himself throughout the trip. Now he has a fever blister on his lip, a reaction to stress. The lip splits painfully all the way across, attracting flies. But the stress can only deepen. There is a lot at stake, and not just the welfare of his son. The seven-figure book advance has paid for the filming of *The Horse Boy*, a trust fund for Rowan, and a school in Texas to offer Rowan's education to others. The school, Big Sky, is to have four or more Betsys as mobile classrooms, each with a felt blanket on her back to use as a blackboard. It will take between nine and 15 children with Rowan's form of autism, and up to 25 siblings. It is due to open next year, and the

plan is to foster replicas around the world, including in Britain. But, after the story of *The Horse Boy*, will any parent want their child there?

Big Sky is being run by the fourth star in Rowan's universe: if the first three are his parents, Betsy and ancient healers, then the fourth is his school tutor, Katherine Sainz, whose son has autism similar to Rowan's. At an old hippie commune in 200 acres of woods, she fits Rowan's day around his needs. He spends four hours touring the woods with his "shadow", Kamilo, who keeps him safe and uses chance discoveries as an educational tool. When he has run off enough energy to be calm, he goes into the classroom, where Sainz is assisted in lessons by two pigs, two cats and a python. After school, he goes riding with Rupert. Rowan's reading is at the level of a seven-year-old. His imaginative play might have arrived late, but it is rich.

According to Kristin, this liberal approach means it might take three times as long to change a child's behaviour. But because the changes come from inside, not outside, they have power. Rupert makes an analogy: if you don't train a horse to think for itself, you won't have a champion. You have a horse that can function under certain conditions in a predictable way.

Their son is a happy and adaptable child. But there are limits. Sainz is thousands of miles away. Rowan's grandparents are thousands of miles away. Everything familiar is far away — except the film crew, the parents, and the unwanted horse.

Rowan suffers an appalling regression and begins behaving in ways not seen since he was 18 months old. He loses his language and starts to babble. He screams uncontrollably at the sound of a cow, assaults a little Mongolian girl, and bites his father. Getting the distressed child to the sacred waters — the "brain spring" — means wrestling him there. And it's all being recorded on film for *The Horse Boy*. As the water is dropped onto his head he screams again. But then he starts to laugh, and washing in the spring turns into a game. Suddenly he's all sweetness.

It's not all bad. There has been a breakthrough so significant that at the time, before all this distress, Rupert and Kristin felt that perhaps the trip was justified: for the first time in his life, Rowan has a friend. In the past he has managed parallel play, where a child plays next to another of the same age. This is different. Our guide has brought his six-year-old son, Bodibilguun, and — helped by the equality of having no common language for Rowan to fail in — they are playing with swords, hugging, riding together briefly and generally acting like friends. And now that he has recovered, Rowan is obviously happy. He makes up a story about his imaginary friend Buster and a little girl rabbit and Blackie the hippo having an adventure in Mongolia, and it is clear that he is reflecting on the events of the past few days. Such storytelling is new for him. The trip is not a disaster, then. But until now the horses have had little to do with it, and then the journey takes another turn downhill.

With everyone, including Rowan, on horseback to see a shaman no 4x4 can reach, Michel Orion Scott, the film director, falls behind. He has food poisoning. Soon he is on the ground, vomiting and defecating, and while he is prostrate, his horse escapes. Surely this cannot get worse.

For 40 appalling years, medical dogma held that autists had no inner life; or if they did, it could never find expression. One mother changed that. Eustacia Cutler taught her daughter to read, worked with teachers to bring her repeatedly out of her own universe, and searched ceaselessly

for the keys to a meaningful future. The girl seemed destined for an institution: even her father expected it. But the daughter, Temple Grandin, is now a professor of animal sciences and a star on the autism circuit. She has used her visual powers, and a rapport with cows, to design a third of all the livestock-handling facilities in the US, reducing the anxiety of cattle — and thus helping the meat industry — with innovations that to her seem obvious. Perhaps Rowan's future is similar.

There was no single breakthrough in Grandin's life; she grew through a series of incremental improvements. "There was no magic; there was just doing the best I could," says her mother. "That's the point; that's the talisman."

It's the same story here. Autism is not really a spectrum: it's a constellation of individuals, and what works for one might have no effect on another. "The experts don't know what to tell you," says Kristin, who is one herself. "The best you can hope for is to find another parent with a kid with some features similar to your kid, and try everything." In the end, many parental decisions are instinct, and you do the best you can.

Somewhere out in cyberspace, the website for *The Horse Boy*, written before we set off, has a bolder, more reckless prediction. Under the heading *What Results Do We Expect?*, it says: "Rowan has already reacted radically well to exposure to horses and shamanistic ceremony" With the prolonged exposure to both, we can expect to see radical improvement and recovery on camera of an autistic child's mind opening up to consciousness. For an audience to go on this miraculous journey will make for a rare and truly magical experience of film-viewing."

This looks unlikely. But then it happens. Michel, the horseless film director, comes staggering into camp, and resumes his vomiting so loudly that Rowan is arrested in his play. The five-year-old stands up and asks the first "why" question of his life. Michel, why are you spitting on it? Knowing the significance, Michel croaks heroically for someone to get a camera. Then Rupert makes a fire, and Rowan asks his first "how" question. Daddy, how do you make fire? Two more horses disappear, making three horses gone, but nobody cares. Within days of making his first friend, and hours after getting onto a horse, Rowan is making verbal breakthroughs.

That just leaves his parents' dearest wish: an end to their days of scrubbing underwear. Rowan does not use nappies: he dumps straight into his pants, either standing on his toes or lying down. Rupert and Kristin then wash and change him.

I have promised not to describe the encounter with the final shaman; for that, you must wait for the film. But I can tell you this. The following evening, on a sandbank, Rowan makes the funny little movements that indicate a poo, but this time there is something new: he is holding it. And his father says: "Go on Rowan, take a squat." The entire group calls encouragement. Even Bodibilguun, the six-year-old, gets down to show him what to do. Rowan looks at everyone, ignores them, goes to a further sandbank, then bends his knees and delivers as if he were potty-trained, before scooping up water and cleaning himself. Rupert and Kristin are ecstatic. For the first time in their lives, they have a continent son.

Rowan's meeting with Betsy was chance, and it was chance that Rupert knew how to take advantage. The father used Betsy for everything: language, maths, social scripts such as

thanking the horse afterwards. "I had the time," Rupert says. "I wasn't trying to push him to one side because I was trying to get a bit of work done,

or because I didn't want to read him that f***ing story about Mr Men for the 400th time. I was enjoying myself with him; instead of being upset I had this autistic child that I couldn't reach. I could reach him. And so I felt very fulfilled as a dad."

My last sight of his son is at a house in Berkshire where he is staying with family friends. I say my goodbyes. "Rowan, give Tim a hug," say his parents. I'm nothing to him, really; just a background observer who talks a lot to his parents. But he turns his back on the television without protest, puts his head over my shoulder and his cheek next to mine, and with his hands around my neck and back, we squeeze. For one who faces a life of "extreme autistic loneliness", the touch of those 10 tender fingers are a cause for hope. Would language have come to him anyway? Was he always going to learn how to make a friend? Who can say? All you can know is that, for this child, a liberal, eccentric, deeply loving regime centred on horses seems to be the best therapy possible. We have escaped the dark ages of the 1950s, when autism was blamed on the rejections of a "refrigerator mother" and the child simply hidden away. But we still understand so little. One day we will come out of autism's medieval period; perhaps the story of The Horse Boy will be a milestone on our way.