



of pediatric samples remains one of ATP's most formidable challenges.

Even so, what ATP has accomplished is remarkable: creating the world's largest brain repository exclusively focused on autism research. Nearly 100 publications have resulted from studies undertaken with ATP tissue samples, many of them groundbreaking. The ATP collection includes over 180 samples that were obtained in collaboration with Harvard University's Brain Tissue Resource Center, which stores and processes the tissue. Upon request, this tissue is then distributed to researchers whose projects have been approved by Autism Speaks' Tissue Advisory Board, an impartial, scientific review board that ensures the proper distribution of tissue to qualified researchers. Samples are individually catalogued with well-defined clinical information using a web-based portal designed for the scientific community. Dr. Lightfoot is also initiating a project, in collaboration with a group of scientists in the US, to scan whole brains into high-definition, 3-D images, which can be examined without risk of damaging the precious tissue. This project will digitize a large cohort of autism and control brains for researchers to study and conduct tissue research over the internet. No longer will autism research be geographically restricted only to those few labs that possess samples of this limited resource.

ATP has also started a repository at Oxford University, for launch in the summer of 2009. Led by his UK affiliate, Dr. Simon Wallace, Dr. Lightfoot says the Oxford bank already has collected four brains. Additional banks are planned in Canada and Australia, and a bank in Mexico is on the horizon. And Dr. Lightfoot says they're just getting started. ATP recently partnered with a scientist in California, who has pioneered a technique which involves taking a post-mortem brain biopsy, isolating neural progenitor cells, and then establishing non-exhaustible stem cell lines. Dr. Lightfoot says this project could help resolve a major problem in autism research – that there simply isn't enough tissue to go around.

"Part of my job is to see where the science is going," he said. "But with more demand for research, there's more demand for tissue. And, as large as we are, we only collect about 20 to 25 brains a year."

Dr. Lightfoot's concern about the lack of donated tissue is a common one among disease researchers; it is consistently cited as a roadblock to medical research progress. The dearth of donated tissue makes each donation more precious; each donation is the ultimate contribution in the search for a cure. There is no greater gift.

"There is absolutely no way to resolve these issues without tissue," he said. "It is the only way to study it on a cellular and molecular level. Until we get a larger prominence in the public mind, the field is going to be held back."

### *An Act of Generosity*

By his parents' accounts, Reid Thompson, like so many other autistic children, began his life as a typical, happy baby.

Eventually, they noticed worrisome changes in his behavior.

"He just began to slip away," said Chereen Lopez, Reid's mother.

"He was just an incredibly spirited child. Really happy and outgoing, yet required a lot of structure," Chereen said.

Reid was diagnosed with autism just before his third birthday.

"We were thrown for a loop," said Brian Thompson, Reid's father. "We knew nothing about autism."

Chereen and Brian immediately immersed themselves in the autism community, seeking occupational and behavioral therapists to work with Reid.

"He didn't have a lot of language, but that had started to improve over the last couple of years, before he passed, in great part through the therapy he was doing," Chereen said.

In August 2007, Reid's stepmother, Kristin, went into Reid's room to wake him for summer school. She found him unresponsive; rescue efforts were unsuccessful.

"We don't know how Reid died," said Kristin. "The Medical Examiner wasn't able to give us a conclusive answer. I don't think we will ever have an answer."

His devastated family was determined to make sure that Reid's contribution to the world wouldn't end that awful morning. "We as parents agreed that we really weren't done," said Brian. "That's how we came upon the ATP program."

The day after Reid's death, a fellow parent in the Ventura County (CA) Autism Society told Reid's parents about tissue donation through the ATP. The family didn't hesitate.

"Reid was a teacher," said Brian. "He taught all of us about compassion, and patience, and acceptance. We were truly gifted and grateful for everything that he gave us. The Autism Tissue Program enables Reid to continue to teach and contribute to helping find a cure."



Reid Thompson passed away in 2007; now through the ATP, he is helping researchers understand autism's effects on the brain

*"One of the important messages we want to send to the medical community is that we need to improve and understand [tissue] harvesting techniques. When our world had been turned upside down by this loss, we asked the Medical Examiner to take everything that would be needed, to preserve as much as possible, because our son isn't done with his work helping others. Now scientists are learning that there may be better techniques that could have made his donation even more useful."*

--Brian Thompson, father of Reid Thompson, ATP Donor



Reid's family and friends tell his story at community events like Walk Now for Autism

"It would have been a disservice to him not to do it," Brian said.

The biggest challenge facing the ATP – beyond the delicacy of the subject – is educating families about its existence, and communicating to shattered families the utility of the program. "It's the last thing anyone wants to think about," said Brian. But, he noted, the ATP gives families a unique opportunity to honor the memories of their loved ones. Reid's family was told recently that their son's brain tissue was used in an autism study.

"To hear about Reid contributing to a study kind of gives all of us more reason to be proud parents," Brian said. "We are so grateful to the scientists who are conducting this groundbreaking research. We are honored as a family that our beautiful son Reid is contributing to finding a cure."

"He had worked so hard his whole life," said Chereen. "We never thought twice about donating his tissue. He's the greatest teacher of all now. His contribution, along with the contribution of others, is hopefully going to help a lot of people."

Giving, even in grief: the ultimate act of generosity.

Learn more about Autism Speaks and the Autism Tissue Program at [www.autismspeaks.org](http://www.autismspeaks.org) and [www.autismtissueprogram.org](http://www.autismtissueprogram.org)

**COMING NEXT:**

**Part 2, the Autism Speaks Autism Genetic Resource Exchange (AGRE)**