SCRIPT

Florida dad receives first-in-world ALS treatment

VIDEO	AUDIO
Anchor lead-in	ALS is a nervous system disease that affects nerve cells in the brain and spinal cord. Worsening over time, ALS affects control of the muscles needed to move, speak, eat and breathe. For Dr. Rakesh Parekh (rah-KESH PA-rek), a father of three and physician, the diagnosis doesn't define him – it has motivated him to find a way forward.
RAKESH PAREKH, M.D. **Patient**	"Healthcare is what I've done for almost 25 years. Where I work, the stretchers all have blue linens, and to be on the blue sheet is a completely different experience."
	After muscle weakness began to affect his movement, Dr. Rakesh Parekh was diagnosed with ALS in 2020.
RAKESH PAREKH, M.D. **Patient**	"You get this diagnosis, and, you know, within 3 to 5 years, you're no longer."
	Initially working with a care team closer to home in Orlando, Florida, Dr. Parekh was determined to find a way to preserve his quality of life and possibly help others.
TEJAL PAREKH **Wife**	"Got the test results back, and they told us what the mutation was, the specific gene, and so we started kind of researching and reached out to physicians, researchers all over the country, all over the world. We have three children and they all have a chance of inheriting this gene. To date, there isn't much out there for people who get diagnosed with ALS. There's not a lot of treatment."
	That's when they learned about the work of Dr. Bjorn Oskarsson, a Mayo Clinic neurologist.
BJORN OSKARSSON, M.D. **NEUROLOGY** **Mayo Clinic**	"Individualized medicine is not just providing individualized medicine, it is taking care of the individual."

	After nearly two years of testing and preparations, hope came in the form of a treatment in April 2024.
BJORN OSKARSSON, M.D. **NEUROLOGY** **Mayo Clinic**	"For Dr. Parekh, his genetic abnormality is an extremely rare cause of ALS. So we worked with our outside partner to develop an individualized treatment made just for him. And he is the first person in the world who has received this treatment. This gene-stopping therapy can shut down the production of the protein by tackling the gene abnormality at the RNA level. We've been able to stop his disease progression, and we are seeing some really, really exciting early results."
	One year after his treatment started, Dr. Parekh and his family have hope. The process has also changed how he approaches his work in healthcare.
RAKESH PAREKH, M.D. **Patient**	"Not only has it made an impact on our lives, but it honestly, it's made an impact on the way I practice because I realize now what patients need beyond healthcare."
	For the Mayo Clinic News Network, I'm Alex Osiadacz (Oh-side-us).