

Scientist develops treatments for rare brain diseases

Jimmy Chow

For more than two decades, Professor Edwin Chan Ho-yin has pursued one of medicine's toughest challenges by developing treatments for rare neurodegenerative diseases.

His pioneering work, now channelled through his biotech start-up Rare Power, bridges academic discovery with real-world application, earning him a place as a finalist in this year's Spirit of Hong Kong Awards in the innovation category.

The Spirit of Hong Kong Awards, co-organised by the Post and Sino Group, recognise the efforts of the city's unsung heroes who contribute to the community or inspire others with stories of how they overcome personal challenges.



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PROFESSOR EDWIN CHAN

Chan's path as a scientist has been shaped as much by empathy as by intellect. He began his research career in the United States but decided to return home in 2002 after reading a Hong Kong newspaper article about patients suffering from spinocerebellar ataxia, a rare genetic disorder that affects balance and coordination.

"I remember sitting on the plane with that paper in my hand," he recalled. "It struck me that if Hong Kong has patients in need, we should also have scientists working for them here. That story brought me back."

At Chinese University (CUHK), Chan established one of the city's first research programmes dedicated to rare neurological diseases. His team later helped form a patient registry that linked doctors, researchers and families who had long been isolated.

"In the beginning, we barely had a handful of patients. Now we have almost a hundred. Behind

each name is a family that finally feels seen," Chan said, explaining the research had, from the start, been driven by compassion.

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After two decades of laboratory breakthroughs, he founded Rare Power in 2023 to bring his discoveries closer to patients.

Supported by CUHK and Hong Kong Science and Technology Parks under its Incu-Bio Programme, the company develops peptide-based biologics that target toxic molecules found in diseases such as Huntington's, amyotrophic lateral sclerosis and frontotemporal dementia.

"We design therapeutic peptides that bind to and neutralise the faulty RNA and proteins that damage brain cells. It's like giving the cell a rescue signal, a way to clear the molecular clutter," Chan said.

Rare Power also runs RareBank, a biobank and data-sharing platform that collects genetic samples and information from patients to accelerate diagnosis and treatment.

For Chan, the transition from academic scientist to entrepreneur was not easy. "In academia, you teach and others listen. In business, you have to persuade people to believe," he said.

"It's humbling, but it teaches you that science only matters when it touches someone's life."

Chan said he found meaning in stories that mirrored his own journey. One of his inspirations was the 2010 Hollywood film *Extraordinary Measures*, in which a father and a scientist join forces to develop a treatment for children with a rare disease.

"That story showed me that science is not just about formulas but rather about courage, persistence and love," he said.

In addition to his research, Chan advocates for patient welfare and community understanding. For example, he works closely with Lifewire, a charity supporting children with rare diseases. Earlier this year, he joined them for a charity screening of *My First of May*, a new Hong Kong film exploring illness and resilience.

"Maybe we can't cure every rare disease in my lifetime," he said. "But if we can leave behind knowledge, compassion and a community that keeps moving forward, that's already success."

Asked how he defines the Spirit of Hong Kong, Chan shared an image from his phone showing the words "reality, equality, equity and justice". "The city's true spirit lies in removing barriers so everyone can stand tall," he said.



Edwin Chan established one of the city's first research programmes dedicated to rare neurological diseases at CUHK. Photo: Kong Yat-pang