



Cross-border treatment for rare bone diseases: an interview with Dr Michael Kai-tsun To

Dr To examining a child during the 2022 Wishbone Day at The University of Hong Kong–Shenzhen Hospital

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Dr Michael Kai-tsun To is a paediatric orthopaedic surgeon and well-known expert in osteogenesis imperfecta (OI). He received training in orthopaedics at Queen Mary Hospital, where he now offers his expertise; he also serves as a clinical associate professor at The University of Hong Kong (HKU). Since the establishment of the HKU-Shenzhen Hospital in 2012, Dr To has travelled between Queen Mary Hospital and Shenzhen to provide cross-border care for children with bone diseases. Dr To's dedication to children with rare bone diseases was recognised in 2018 when he received the Hong Kong Humanity Award.

One of Dr To's most important projects has been the establishment of a rare bone disease centre in Shenzhen, where he provides medical expertise to families from multiple provinces in China. Although it is now a full-fledged specialist service centre, it originated from rather humble beginnings.

Osteogenesis imperfecta is a rare, heritable brittle bone disease with a prevalence of 1 in 10000. Patients with this disease may exhibit deformities and can easily develop fractures. Although treatment is available, it is prohibitively expensive; because OI is rare, specialists with relevant expertise are often difficult to find. Although relatively few patients with OI attend the Duchess of Kent Children's Hospital (DKCH) in Hong Kong, one such patient contributed to the establishment of the OI service now thriving in Shenzhen.

Around 2012, while working at the HKU-Shenzhen Hospital, Dr To provided follow-up care

for an adult patient with OI. Many years prior, when Dr To was still a medical student, the doctors at DKCH had performed complex surgical treatment of OI in this patient. The patient had presented to DKCH with difficulty walking; after surgery, he regained the ability to walk and subsequently moved to Guangzhou. The grateful patient asked if the new hospital could help other patients with OI as he had been helped in childhood. Through this patient and various WeChat patient groups, numerous families caring for children with OI found their way to the HKU-Shenzhen Hospital.

The rare bone disease centre expanded organically in response to the overwhelming demand. Since then, the centre has gained sufficient recognition that it has been the site of more than 1000 surgical treatments for children with rare bone diseases. When asked how he came to devote much of his career to caring for these children, Dr To jokingly quoted a Hong Kong action movie *Shock Wave*, in which an explosive ordnance disposal specialist (portrayed by Andy Lau) explained that he did not enter into the profession by choice—it was a matter of fate.

Today, the centre is well-known throughout Mainland China for its expert management of OI. The journey from its beginnings in the early 2010s to its present success has been filled with challenges. In particular, substantial time and effort were needed to establish patient trust in a treatment that was relatively unknown. Initially, there were rumours in patient WeChat groups that Dr To was a 'liar' for

claiming that surgery can potentially restore mobility in patients with OI. However, the increasing number of patient success stories gradually outweighed the distrust and doubts.

As the service expanded and demand grew, Dr To travelled from Pokfulam to Shenzhen each day before 7 am, returning across the border at 6 pm. Cross-border travel became more difficult during the early portion of the coronavirus disease 2019 pandemic because of lengthy quarantine mandates. To address this situation, Dr To sacrificed time with his family and coordinated with colleagues to ensure that clinical services in Hong Kong continued smoothly in his absence.

Through the OI centre in Shenzhen, Dr To gained knowledge of the unique challenges encountered by patients with OI in Mainland China. Many patients travelled great distances and incurred substantial financial burdens to reach the HKU-Shenzhen Hospital. In one memorable case, a mother with OI (and height of <1 m) and her son with OI travelled for 40 hours to reach the OI centre. Recognising the great need for medical care outside of major cities, Dr To led service trips across the country, including visits to Yunnan, Sichuan and Tibet, to provide medical care and train local medical professionals. Local residents often eagerly waited for the medical team's arrival, and they offered unexpected tokens of gratitude to the doctors. Dr To recalled that one patient brought a freshly slaughtered chicken to his clinic! He also recalled the story of a 17-year-old boy with OI in Sichuan, who complained of tongue pain refractory to high doses of analgesics. He had not received a proper diagnosis, despite multiple specialist consultations. Upon arrival, Dr To's team promptly made the diagnosis of basilar invagination as a complication of OI, then obtained funding to help finance the boy's treatment. After regaining full use of his tongue, the boy greeted everyone by proudly sticking his tongue out.



Dr To (bottom) with Hong Kong Medical Journal Student Reporters Natalie (left) and Michelle (right)

In addition to providing unforgettable anecdotes, the sincere gratitude from patients during these service trips encouraged Dr To and his team to continue their cross-border efforts. In 2020, Dr To and his team received a special research grant from the Chinese government to support their OI clinical service and research—it was a well-deserved moment of recognition for sustained effort over the past decade.

The OI service in Shenzhen has also delivered unexpected gains in Hong Kong. Because of the high patient volume in Shenzhen, the HKU team has become internationally renowned, leading to multiple research and training opportunities. At the time of writing, Dr To and his team are preparing to host the 2025 OI conference in Hong Kong—the first OI conference outside of Europe and North America. This great honour is expected to inspire further developments in OI research and treatment in Hong Kong.