

# Long life and love comes true for patient with chronic aplastic anemia

Tan Weiyun

In the warm glow of a winter afternoon, Zhang Jiong, 52, sits with a gentle smile that belies the tumultuous journey he has traversed. Labeled a “Time Bomb” due to his precarious health, Zhang’s life seemed destined for a tragic end. Yet, against all odds, he sits here today, not just as a survivor, but as a beacon of unwavering hope and resilience.

As he reflects on the past several decades, his eyes, mirroring a life filled with both pain and triumph, tell a story far more profound than words could capture.

“I’ve been stable these years,” he says, his voice a calm river flowing through the rugged landscape of his life with chronic aplastic anemia, which has shadowed him since a misdiagnosed treatment at 6 years old.

“Perhaps I am so far the longest-living patient with this condition,” he muses.

Despite the relentless cycle of the disease, Zhang’s spirit remains undiminished. “It recurs, like stock prices, up and down. I’ve had to constantly seek new medications from year to year due to resistance,” he says.

Zhang’s childhood was marked by vulnerability and fear, grappling with the twin threats of bleeding and infection. He recalls an incident in primary school, a nosebleed so severe it led to an emergency hospitalization. “After a blood transfusion, I felt strong enough to take on a tiger, but that vigor would wane in days,” he reminisces.

The invisible and spontaneous bleeding was his constant nemesis — during conversations and in his sleep, often occurring without any warning. He might suddenly feel blood trickling from his ears or find his mouth bleeding. More hidden and dangerous were instances of subarachnoid hemorrhage: invisible losses of blood that carried unpredictable risks.

Sometimes, Zhang wakes at night to find damp spots on his pillow, silent indicators of bleeding probably from his ears or nose, reminding him of his body’s fragility. There is also unseen



Zhang Jiong’s wife and elder daughter in France during a family trip to celebrate their 10th anniversary of marriage in 2014

bleeding, such as in his stomach, which are often more terrifying than visible wounds, as they are harder to notice and control.

Due to an incorrect dosage of chloramycetin following dysentery at 6 years old, the medication hindered the development of his bone marrow and impaired its ability to produce blood — a condition known as chronic aplastic anemia.

This resulted in significantly reduced counts of platelets and white blood cells in Zhang’s body, leading to severe limitations in physical activities such as running, jumping, or prolonged walking. His body’s inability to generate sufficient blood necessitates regular transfusions to sustain his life.

“It’s best to think of it as a chronic illness, like high blood pressure or diabetes,” he says, with a voice of acceptance and black humor. After years of battling the disease, he has come to terms with his health situation, viewing it not as a relentless enemy but as a constant companion that needs careful management.

Zhang now administers a nationwide online support group, spanning social network platforms like Baidu post bar, Xiaohongshu, Douyin and Bilibili, where he connects with hundreds of fellow patients. They seek his advice on understanding lab results and medication suggestions. “Having lived with illness for so long, I feel obliged to help those newly diagnosed,” he says.



A family photo at the seaside

Zhang understands the panic and confusion that a new diagnosis can bring, leading many to seek hasty treatments. He advocates following guidelines by the World Health Organization, emphasizing that immediate bone marrow transplantation, often considered by many, is risky and should be a last resort.

“I’ve seen too many patients sell their homes to incur huge debts for the surgery, only to lose their lives in the end,” he says.

Leading the group for over six years, Zhang has received both gratitude and criticism, and even had his accounts reported and groups shut down. “Because I advise against immediate bone marrow transplants, it conflicts with the interests of some people involved in the industry, leading to frequent reports against me,” he explains.

## Extending a helping hand

His role extends beyond mere advice. Faced with a health crisis for himself and his fellow patients, Zhang exhibits determination and bravery akin to Ron Woodroof from the movie “Dallas Buyers Club.” While Woodroof fought for the rights of AIDS patients, Zhang’s battle is for those suffering from chronic aplastic anemia.

He sourced a cost-effective steroid medication that was unavailable in Shanghai pharmacies due to its low profitability. Determined, Zhang traveled alone to the drug’s manufacturer in the Guangxi Zhuang Autonomous Region.

There, he met with the sales manager, forging a connection that would become crucial for many. “I made regular inquiries about where the drug was distributed near Shanghai,” he says.

Upon learning that the medication was available in Hangzhou, Zhejiang Province, Zhang took on the responsibility of not just his own needs but those of his entire support group.

He collected their prescriptions and personally coordinated the purchase of the medicine. “But I made sure that all the money was directly transferred to the pharmacies,” he clarifies. “I didn’t want to handle the finances myself, to avoid any legal complications.”

Zhang’s current regimen is a careful balance, a cocktail of medications aimed at maintaining equilibrium in his fragile health. “I’m on immunosuppressants now,” he says. “They suppress everything — the good and the bad — in an effort to stabilize my blood. It’s about keeping everything in balance, slowing down my metabolism regardless of the cell type.”