The Dream of Life
Spurred by their fight against lupus, Helina Chan and Odile Benjamin want to support rheumatology research to benefit sufferers like themselves, as Grace Ma finds out.

Fine art gallery appreciation turned 15 last year and its founder and managing director, Helina Chan, will tell you that the biggest hurdle to the gallery’s success was not the work involved in promoting Asian artists but her health.

Helina started feeling unwell in 2005, six years after she established the gallery in Singapore. It was the start of many visits to different doctors as she faced one painful condition after another, including asthma, severe water retention and numb chin and limbs, before she was diagnosed with hypothyroid that year. Her thyroid condition stabilised for a while but she started having nosebleeds and a leaking kidney in 2011. It was only then that she was told that her hypothyroid was autoimmune related and she was found to have lupus, a condition where the immune system attacks organs including the kidneys, brain, blood vessels and skin.

Helina says, “The hardest part was not being able to tell my parents what was going on. I had flare-ups with lesions on my face and was still running around travelling, meeting clients and artists, and managing both my galleries in Hong Kong and Singapore then.”

For Odile Benjamin, who is the divisional chief executive officer and co-creative director of FJ Benjamin, her lupus diagnosis could not have come at a worse time. She and Douglas Benjamin had just married and moved to Singapore. Odile kept falling sick and though it was bronchitis at first.

“Although I was lucky to be diagnosed accurately within four to five months, there were doubts if it was really lupus because I also had inflammation of the heart. We were also told that I may not have children or it would be dangerous for me to do so. It was a bleak picture.” She persevered through 22 years of medication and treatment, including regular steroid intake. Few knew that she was ill and Odile went on to have four healthy children, now aged two to 20.

For many rheumatological diseases, the immune system attacks the body resulting in inflammation of affected organs that can lead to irreversible damage. Diagnosis is difficult and hence, often delayed. Treatment options tend to be limited and in some cases, symptoms cannot be treated but only managed. Over 600,000 people are suffering from rheumatological diseases in Singapore.

While it has been an emotional journey for Helina and Odile, both are determined to turn their experiences into a positive one by helping others who are facing similar illnesses. In November last year, Helina launched the Revere Rheumatology Research Fund, in conjunction with iPreciation’s 15th anniversary celebration. Odile is a committee member helping in its fundraising efforts and they target to raise $3m in the first two years and eventually $12.5m in the mid to long-term, with the government potentially matching the funds raised dollar-for-dollar.

This will benefit research under the SingHealth – Duke-NUS Medicine Academic Clinical Program on new treatments with fewer side effects and improved outcomes for patients suffering from rheumatological diseases. Five key areas are being studied: systemic lupus erythematosus, systemic sclerosis, osteoarthritis, rheumatoid arthritis and spondylarthritids.

Professor Julian Thumboo, head and senior consultant at Singapore General Hospital’s department of rheumatology and immunology, says he is heartened by this initiative as the progress of current rheumatology research programmes is often limited by the availability of funding. “Not only will the Revere fund pioneer important research work in the area of rheumatology, it will have the financial means to retain and even recalls Singapore research talent from abroad to build vital long-term foundations for such medical research work. The fund will also help accelerate research by allowing ongoing projects to be completed faster and be a key source of funding to sustain our core team of trained and committed research support professionals. This way, our researchers can have more time to focus on the scientific aspects of their research.”

Helina and her committee also want to raise a greater awareness and understanding of rheumatological diseases, which so far, are not known to have a cure. Helina says, “People rarely talk about rheumatological diseases as they are so complex. It is my dream that the Revere fund can help researchers find some ways of prevention and eventually cure in my lifetime so that others don’t have to go through the suffering I did.”

To contribute to the Revere Rheumatology Research Fund, visit academic-medicine.edu.sg/MedicineACP/philanthropy-rheumatology-and-immunology.

A CREATIVE COLLABORATION
Art has always been Helina Chan’s first love. To celebrate the 50th anniversary of her fine art gallery, iPreciation, Helina gathered its stable of artists for a special cause—the launch of a long-term charity platform dedicated to building and growing research for the area of rheumatology. Artists like Mihelko Prvacki, Lea Wen, Tran Bok Chiong, Choh Ei Kay, along with eminent Taiwanese artist and sculptor Ju Ming, each contributed an artwork for auction at a benefit dinner held in November last year. The Revere Rheumatology Research Fund has raised about $950,000 to date, with the government potentially matching the funds raised dollar-for-dollar.