

BEHIND THE NEWS CHILDREN'S HEALTH

A new book documents the outstanding courage of severely ill children and their families and highlights pitfalls in their treatment. *Linda Yeung* reports

Living beyond the pain

Tahir Mohammad was only eight months old when he had a bone marrow transplant, the only source of hope for the boy plagued with a hereditary disease called severe combined immunodeficiency (Scid).

The operation had been successful, sparing him from fatal infections. But for the past decade, 11-year-old Tahir has been in and out of hospital every three months for injections necessary to bolster his immune system.

Tahir is among scores of child patients across Hong Kong who have fought long battles with severe diseases, some of which doctors have only limited knowledge about.

Several months after he was born, Tahir was afflicted with multiple infections, but the doctors treating him could not determine why. Because of his weak physical state, he had to be hospitalised for six months, undergoing frequent blood tests, before he could receive the bone marrow transplant.

The delay prolonged his suffering and that of his family. "It was the toughest time in my life," recalled his father, Mohammad Tufail. "I had to go to the hospital after work each day, and send my older daughter to Pakistan to be taken care of by relatives there, since my wife and I could not look after her. I

saw Tahir taking frequent blood tests. I knew it was all necessary, but it was nevertheless very heart-rending."

Now, Tahir is as active as any child his age; he enjoys playing football and other activities. His father, a devout Muslim whose faith has helped him face his son's illness, counts himself lucky that the city's medical costs are affordable, much more so than in Pakistan.

The perseverance of families like his is documented in a book entitled *Robust Under the Gust*, published recently by the University of Hong Kong's Department of Paediatrics and Adolescent Medicine on its 40th anniversary.

Head of the department, Lau Yulung, wants to enhance public awareness of child patients, especially those stricken by rare diseases. He estimates there are about 10 immunodeficiency cases among children in Hong Kong each year. The lack of public knowledge about them and others could delay treatment and hamper their chances of a full recovery.

"In Tahir's case, the chances of a successful transplant would be higher the earlier the diagnosis was made," Professor Lau said. The treatment process for Tahir's younger sister, Bibi, also born with Scid, was much smoother. Professor Lau carried out a blood test for her hours after her birth, and a



Margaret Chiu Chung and her son Leon (above). Tahir Mohammad and his sister, Bibi (below), had bone marrow transplants. Photos: Courtesy University of Hong Kong

transplant was performed at an early stage. The 10-year-old has been freed from any medication since she was three.

The bilingual book puts together the cases of 33 courageous children. Two who survived their excruciatingly painful childhood are now medical students at local universities. One child was stricken by leukaemia – the most common cancer in children with an incidence rate of about four per 100,000 – at the age of seven, while the other patient was 11 when she was diagnosed with a rare form of cancer with a survival rate of about 60 per cent.

Others in the book were suffering from diseases such as dyskeratosis congenita – a rare hereditary disease which affects the skin, nails and hair – thalassaemia and rheumatism.

There are cases like Primary Three pupil Leon Chiu, who had an operation to have a pacemaker installed near his heart as soon as he was born. He was

diagnosed with the rare condition of congenital complete heart block that causes irregular heartbeats. And every few years, his pacemaker is replaced.

In November 2003, he was rushed to the emergency ward after the wire of his pacemaker broke and his heart stopped beating. He had fainted at school and would have sustained head injuries had his classmates not rushed to support his head.

A month after the emergency operation, he underwent more surgery after doctors found that the wire of his new pacemaker had moved.

"It was a big trauma for us. Since then he has become worried easily about the chances of dying whenever he feels uncomfortable," said his mother Margaret Chiu Chung Wai-ling, founder of the Regeneration Society dedicated to helping chronically ill patients of all ages.

Despite also being burdened with dyslexia, Leon is an avid reader, plays the piano and has won several speech contests. "He has a good memory and an IQ of above 140. Maybe that is a compensation from God," Mrs Chiu said. "Fortunately my husband and I are professionals and can afford the financial burden."

Mrs Chiu said she also received plenty of comfort and support from people around her. "My eldest son loves Leon and he wants to be a medical researcher in future to be able to help him. Our family values each day we spend together. The parents of Leon's classmates said they and their children have learned much from his optimism, positive attitudes and strength."

Copies of the book, also featuring portraits of the patients and their families taken by renowned photographer Yip Ching-lam, are in Queen Mary Hospital's paediatric ward to encourage parents of the chronically ill.

Professor Lau believes increasing public awareness would promote the need for more financial support for families unable to afford the special drugs that their children need to live.

"Hong Kong is at a primitive stage in public knowledge about rare diseases like immunodeficiency," he said, add-



ing that the whole world faces the issue of the high costs of drugs required to save people.

In the past he has negotiated with overseas charitable foundations to provide financial support for child patients who cannot afford the expensive rare drugs. He is seeking sponsorship for one of his patients who has a form of immunodeficiency.

"The problem is that pharmaceutical factories around the world are reluctant to produce drugs for rare diseases, and even if they are made the local Hospital Authority may not necessarily get them due to financial reasons," Professor Lau said.

Staff at teaching hospitals of the University of Hong Kong and the Chinese University of Hong Kong had only limited experience in tackling the diseases, he admitted. "We have a unified protocol for child diseases at both universities but not for the rare illnesses."

"We need to keep accumulating experience in dealing with them and adjust our methods of treatment accordingly. There is also a need to organise better support services for patients."

Professor Lau said a primary care system for children should be set up in the city to allow for the early detection of diseases and keep systematic records on a child's medical history. "The problem now is parents tend to go from one

doctor to another when their child falls sick and has not gotten better. They want an instant cure."

"In other countries, children are looked after by family doctors who know about past medical problems that their patients have had," Professor Lau said.

In mainland cities such as Shanghai and Chongqing there had been improved understanding of children's diseases and more attention was given to early diagnosis, he added. Apart from medical treatment, parental support was also essential for helping a child overcome severe diseases.

Tahir's father urged parents not to give up on their sick children.

"I saw one who did not return to the hospital again to see her child. I don't know what happened to the child afterwards. Some parents get angry with their doctors, asking why their children have not got better."

"I think sometimes parents have to control themselves when their children fall sick. Our children are given by God and our job is to take good care of them."

Anyone interested in buying *Robust Under the Gust* can call 2817 0641. Proceeds will cover the costs of the book's production and circulation, and health improvement projects for sick children.

TRANSPLANT PUTS ANGEL ON HER FEET

For years, 13-year-old Angel Lee had put up with excruciating pain in her bones, caused by a rheumatic disease rare among children.

Diagnosed with juvenile idiopathic arthritis at the age of three, the Form Two student suffered deformed joints and swollen knees that made her unable to walk. Until she underwent a bone marrow transplant in 2001, she had to rely on a walking stick.

The amount of medicine she had to take, including steroids and pain killers, put her arthritis under control, but they also brought about side effects such as dizziness, stomach ache and hip pain.

The operation – a pioneering procedure at the time – brought relief to her family. Angel's mother, Lee Yuen Wai-ting, used to carry her all the way from home to her classroom in a nearby school.

"She felt particularly painful in the morning and we had to coax her



Angel's mum provides crucial support

to get out of her bed each day. Her joints were stiff and she was unhappy. I felt helpless when doctors said hers was an incurable disease. We had not expected that advancements in medical knowledge would provide a solution."

Now Angel can walk freely, but due to excessive consumption of steroids, her problem of hip pain remains. Doctors have warned that

a major operation to replace her hip joints would be necessary but it is best to be put off until she is older – provided her condition does not deteriorate.

But the disease has not driven young Angel to despair. She has done well in school, encouraged by the people around her. Her teachers give her inspiring books – including publications by the late Taiwanese author Liu Hsia, who suffered from the same disease as her – and students send her cards whenever she needs to undergo treatment. Then there is the support she gets from her family.

"She is our only daughter; I and my husband have devoted all our attention to her," said Mrs Lee, pleased with the strength her daughter has shown. "She is more mature than many children her age, perhaps because she has been to the hospital a lot and seen a lot."

Linda Yeung

'Ion man' seeks to tap acceptance for his water solution

A souped-up form of water has been overlooked as a killer of lethal viruses and bacteria, writes *Skip Kaltenheuser*

The misery wrought by the Asian tsunami also brought frustration to many who sought to help but ran into logistical barriers. Among them was Hoji Alimi, an Iranian-American who read sadly of children who became amputees or died after infections of small wounds that should have been easily treated went on rampages throughout their bodies.

Mr Alimi's company, Oculus Innovative Sciences, based in California, takes two simple materials, water and salt, and creates a form of highly oxygenated water: the result looks, smells and tastes like water, but carries an ion imbalance that makes short work of single-celled organisms. Complicated cellular structures, like people, animals and plants, need have no fear. But bacteria, viruses, spores and fungi that get a splash quickly check out as their cell membranes collapse.

The company has perfected an ionisation process which allows the capture of particular species of ions used in a controlled formula of free ions.

Single-celled organisms are surrounded by the water, in which the oxygen atoms, each short of an ion, act as ion thieves to rebalance themselves. This fractures the cell's membrane integrity, like a weak spot in a dyke. The action is quick – depending on the microbe up to 30 times faster than alcohol, which doesn't kill spores. Because it's not bleach-based, high levels of chlorine are not required to increase the kill rate, and of course it won't catch fire.

If a child accidentally sips the water, he gets a bad case of clean teeth.

But it sounds like science fiction and in the rush to provide assistance, says Mr Alimi, volunteers



Amar Pal Singh Suri, who operates a diabetic foot care clinic in Delhi, is treating his patients with Microcyn. Photo: Dan McFadden

stayed with the familiar. No one picked up on his offer of the souped-up ionised water, dubbed Microcyn.

Mr Alimi doesn't court disaster, but he knows sooner or later nature or man will usher in something onerous. If so, he's likely to get a more knowledgeable reception the next time he offers help.

Government approvals for diverse uses from disinfectant to wound irrigation have come from

the US, Europe, Canada, Mexico and, pending, Bangladesh. Doctors conducting trials in Mexico and India are recounting stories at international conferences of their surprise at another feature of Microcyn – that it speeds the healing of severe burns and of diabetic ulcers.

Dr Amar Pal Singh Suri owns a diabetic foot care clinic in Delhi, India, where he began experimenting with Microcyn after learning of it last year in Germany. Trying it on a

severe necrotic wound of a patient whose only remaining option was amputation, Dr Suri was surprised to see rapid improvement and the growth of healthy skin tissue.

"I shifted my other patients onto Microcyn treatment," says Dr Suri, "and we are now treating more than 50, with very good results". India leads the world in diabetics, with 37 million. "Every year," says Dr Suri, "diabetics in my country suffer a million foot or lower leg amputations". Personal tragedy aside, "saving a foot is a quarter the cost of amputation and an artificial limb", he says.

Dr Fermin Martinez, president of the Mexican Diabetic Foot Association, had similar results. "Mexico was the first country to obtain the technology and give regulatory approval. I was most sceptical, but one of my colleagues noticed that the horrific odour of diabetic wounds had disappeared."

The stench of decaying flesh is from bacteria. Then physicians observed rapid healing of ulcers that infections had prevented for a decade or more. Dr Martinez chalks this up to the water's unique type of

free ions in the oxygen-enriched environment.

Doctors treating other wounds, such as severe burns in adolescents, also observed the rapid healing, including improvements in skin grafts taking hold and in lessening scar tissue, as well as reduced pain and shorter hospital stays.

Moreover, says Dr Martinez, in addition to "the breakthrough solution of having both disinfectant and wound-healing antiseptic in a single formula, there are none of the toxic effects of disinfectants and antiseptics in common use". The substance is also pH neutral and requires no special handling or disposal. The byproduct is water.

Of particular importance as Microcyn finds its way into a wide array of applications, including conventional products such as wipes, bacteria can not develop resistance to an ionic assault. Among the bacteria that have been rapidly dispatched are the methicillin-resistant *Staphylococcus aureus* (MRSA) and the vancomycin-resistant *Enterococcus*, two antibiotic-resistant customers one doesn't want to encounter.

That signals some of the more promising potentials for this heavy breathing water. Disturbing accounts from Canada to South Africa support assertions that a significant percentage of people in hospitals, perhaps up to 5 per cent, will contract, and frequently die from, antibiotic- and cleaner-resistant bugs.

Last year, in six months, one mutated bug killed 109 patients in 10 hospitals in Quebec, and was a factor in another 108 deaths.

Mr Alimi says his company is now considering delivery systems such as a spray mist, which would sterilise hospital rooms and other areas that face danger from contagions. Such a method could thwart the return of a Sars-like disease, and the economic buffeting that a Sars scare could give Hong Kong, or any city for that matter.

It might also be the answer to the ultimate nightmare, a crossover bird virus that mates with a human virus and creates a bug of the order of the 1918 Spanish flu. Experts say uncounted deaths in remote regions may have rung that pandemic's death knell 100 million times.