

one

The international staff magazine of Credit Suisse
Issue no. 04/2005_published in English, German, French, and Italian

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Roby Molnar walks with the aid of a rollator and combats ALS with computer assistance.

“I No Longer Consider Death a Taboo”

Text Urs Schwarz // Photography Rainer Wolfsberger

“My name is Robert Molnar. I am 31 and suffer from ALS, a terminal illness. ALS patients have an average life expectancy of three years,” is how Credit Suisse employee Roby Molnar introduced himself to the editorial team of “one”. A portrait.

○ _____ In August 2003, while playing soccer, it seemed to Robert Molnar that his right leg had developed a mind of its own. “At first I thought I was just out of shape, but when the condition failed to improve after several weeks, I consulted a doctor – and was referred to a neurologist,” he explains. A battery of tests followed: he was x-rayed, the neural fluid in his spinal cord was analyzed, and his muscle conductivity was checked with electric currents. On June 16, 2004, three days before his wedding, he was diagnosed with amyotrophic lateral sclerosis (ALS), also known as Lou Gehrig’s disease after the baseball player, an incurable and deadly disease that damages the nerve cells responsible for muscle control. Patients gradually lose control over their movements, their muscle cells shrink, and in time, nearly all their bodily functions are paralyzed. “At first, I thought their diagnosis was mistaken and refused to accept it.”

Mixed Reactions

After a two-week honeymoon in Bali overshadowed by fears and worries, Mr Molnar returns to his job in the MIS Tools Production department in Financial Accounting, where he is responsible for the activation of and end-user support for MIS tools such as Customer Reporting. His colleagues don’t yet know the cause of his limp; only his

family and close friends have been informed. Back at his desk, though, he finds himself pondering the inevitable question: “What am I doing here? I’ve been sentenced to a slow death and am dealing with comparatively insignificant matters.” He takes sick leave, but eventually quits his job without ever returning to the office. At this point, he asks that his team be informed of his condition.

He is still in touch with colleagues who knew him well. “My first e-mail to Roby must have sounded a little impersonal; I was afraid of doing something wrong,” says Claudia Widmer. But one e-mail led to another, and the ice was broken. Elke Obermaier, who once shared an office with Mr Molnar, remains close: “I visit Roby regularly. I usually cook a nice meal and we have a pleasant chat.” On the whole, however, his circle of friends has narrowed, he notes disappointedly. He hopes that friends who suddenly became aloof will one day learn to deal with the taboo subject of death. “Sooner or later, they’ll be confronted with it again.”

A former exercise enthusiast, he now relies on indispensable aids, a walker and a wheelchair, and is starting to develop problems speaking, swallowing, and breathing, as well. But instead of burrying his head in the sand, he has decided to use the time remaining to him in a meaningful way. With the help of his wife Nadja, who gives

him the strength he needs, he founded the charitable association StopALS in August to promote and support ALS research. In their apartment in Schwerzenbach in the canton of Zurich, he also maintains the websites www.stopals.ch and www.enjoyyourlife.ch. His goal is to inform a wider public about the disease and solicit donations for StopALS. “It is important for me to support research efforts, even if it is too late for me to reap any benefits,” he says.

Somewhere Out There

He has tried Chinese herbal medicine, acupuncture, and conventional Western medicine – to no avail. He still has a ray of hope each time he tries a new method of therapy, but he banishes any exaggerated expectations. “The lower your expectations, the smaller your disappointment,” is his motto. He is equally pragmatic about well-intentioned references to the astrophysicist Stephen Hawking, who has been afflicted with ALS for decades: “He’s an exception.” In the terminal stage of the disease, patients are fed through a tube and can only breathe with the help of a machine. “I can’t say when I’ll reach the limits of my endurance, but I’m a member of Exit, an organization that supports active euthanasia. I want to be the one to decide when enough’s enough.” Does he think he will ever be able to accept his fate as inevitable? Not as long as he is convinced that a cure will be discovered: “I know it’s out there. It’s simply a matter of finding it.” ○ _____



www.stopals.ch, www.enjoyyourlife.ch