

## STELIOS KYBOUROPOULOS

# Mind over matter

*STELIOS Kybourooulos knows that most people in Greece don't expect to see a quadriplegic doctor in the examining room. He also knows that young disabled people don't usually put "career" at the top of their list. He's determined to change both.*

Kybourooulos has already defied the odds. Diagnosed with spinal muscular atrophy - a genetic, neuromuscular disease - shortly after his first birthday, he has since undergone major, life-threatening surgery four times. He has grown up in a wheelchair. He knows no other way of life. "I have no more reason to be sad than anyone else," Kybourooulos says smiling into the camera.

It's this contagious smile that greets passersby in the street when they stare. He's grown accustomed to the attention, both positive and negative.

"I am used to children staring at my wheelchair," he says. "I see it as part of their education. They often don't know any better."

Nikos Skonis, president of the National Federation of Mobility-Impaired People, works with Kybourooulos raising awareness.

"Stelios is an exceptional young man," Skonis says. "He's an inspiration."

## Rewrote laws

Ten years ago, Kybourooulos made headlines after successfully lobbying the government to scrap a 1974 law banning disabled students from taking part in school parades. Not only did he succeed in rewriting the country's law books, he carried the Greek flag in the 1999 OXI Day parade - an honour reserved for his school's top student.

Today, he continues to surpass most people's expectations. The 24-year-old, who cannot so much as wiggle his toes or cross his fingers, is only a few months away from graduating with honours from medical school at the University of Athens - one of the nation's best. He's the only quadriplegic on campus and plans to become a psychiatrist.

## It hasn't been easy.

"I don't know if I made the



A chapel built next to the house by Stelios' parents

best decision to study medicine because of the severity of my disability," Kybourooulos says during an interview at one of the few wheelchair-accessible beachfront cafes in Athens. "But I don't regret it."

A true trailblazer, Kybourooulos went about changing the face of the university after he enrolled.

"When I started, about 30 to 40 percent of the school was accessible [for the disabled]," he says. "Now, about 80 to 90 percent is accessible. But this came after a lot of effort on my part. I had to push and plea. It wasn't easy."

## Goals

Each new goal requires willpower and inner strength.

"I want to become a psychiatrist," he says. "It's something that I really want. But my worst fear is if my patient asks me to see the doctor. I would just die if this happened to me. A disabled doctor is not something people in Greece are accustomed to seeing."

Still, Kybourooulos believes he will become an exceptional psychiatrist. He knows what it's like to survive loss and disability.

This is one of the reasons Kybourooulos says he wants to do his internship and residency in Sweden, a European Union member state that has generously invested in the so-called system of independent

living.

"That's where I hope to pursue my studies even though it means leaving Greece - the country I love," he explains. "It's important for me to experience life without my parents, and for my parents not to have to spend their entire life helping me. I can't do this here. The fact that I feel as though I am being forced to leave Greece is not a nice feeling."

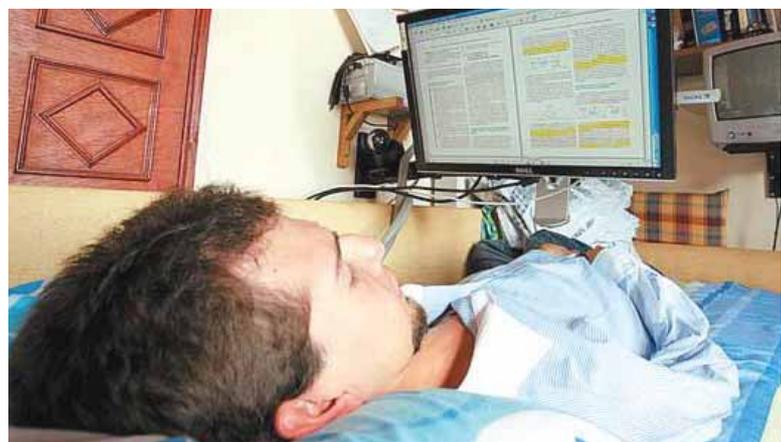
## Independence

The EU statistical agency Eurostat estimates that some 10 percent of the population has some form of disability.

Those with a physical disability face countless hurdles. Few buildings have ramps. The pavement is often too uneven and narrow for a wheelchair, while insensitive motorists



Spiros lifts his brother out of a chair



Stelios Kybourooulos uses a special infrared webcam on his computer to prepare for his biochemistry exam



Mirella helps her son with a drink

park their cars on the pavement or next to lowered curbs blocking access. Public transport - aside from the metro in Athens - is still too difficult to navigate in a wheelchair.

"When I went to Sweden to participate in a conference about independent living last year, I was stunned by how different things are there," says Kybourooulos, who needed help from his brother, Spiros, and a stranger in order to manoeuvre his wheelchair onto the patio of the cafe.

"I saw how the disabled are treated in Sweden - they're equal citizens," he adds. "So equal, in fact, that they have to buy a ticket to enter museums. I was very impressed. It's all about being able to go anywhere you want anytime you want. I hope and pray that this will one day become a reality here in Greece, too."

Kybourooulos' straight-A test scores involve a lot of studying and hard work, as would be expected for anyone. But his studying poses physical and technical challenges others never dream of.

To overcome these, he uses a computer equipped with an infrared webcam that tracks a reflective dot temporarily placed on his forehead. The system was donated by the state. That and a monthly disability benefit of about 550 euros are all he has managed to receive from the government.

In Greece, laws on the rights of the disabled are vague or have been all but shelved. The existing legislation focuses on tax breaks, social welfare benefits and exemptions from military service.

There's also legislation granting family members of the disabled a job in the public sector. But laws to make the city's public areas and buildings accessible to wheelchairs are generally disregarded.

"Even though many buildings these days have ramps, they are not designed properly," Kybourooulos says. "Ramps are usually too steep and impossible to access in a wheelchair without assistance.

It's unfortunate."

## Ratification

Kybourooulos, however, is hopeful the situation in Greece will change. He's pinning his hopes on the United Nations' Convention on the Rights of Persons with Disabilities - a document signed by the government in 2007.

"[However], Greece still hasn't ratified it," he says. "If and when Greece does ratify it, the situation will have to change."

Under Article 9 of the convention, persons with disabilities should be able to live independently and participate fully in all aspects of life. These measures should apply to buildings, roads, transportation and other indoor and outdoor facilities including schools, housing, medical facilities and the workplace. Article 20 of the convention says disabled people must be able to go where they want when they want and at an affordable price.

Only 10 countries in the 27-member EU bloc have ratified the convention. They are Austria, Belgium, Denmark, Germany, Hungary, Italy, Portugal, Spain, Sweden and the UK.

"We have to chase after our rights," he says. "And, if we have the guts, we have to hit the streets. We have to demonstrate to demand our rights. It's something that we haven't seen yet - the disabled demonstrating."

Kybourooulos recently joined a committee created by the National Federation of Mobility-Impaired People to promote independent living in Greece and the rights of the disabled.

"There are very many ideas and many ways for the disabled to feel they are not disabled," Kybourooulos says. "It took me a year of researching it online to fully understand it. And now I understand just how important it is. The only thing on my mind now is for the concept of independent living to become a reality in Greece. This is what I tell everyone."