

The power behind the World Cancer Declaration

→ Simon Crompton

There was a time when the International Union Against Cancer (UICC) was not so international – being focused primarily on Western countries – and not so much of a union – lacking the ability to fight coordinated campaigns. But the escalation of cancer rates in developing countries cried out for a powerful global voice for cancer control. **Isabel Mortara** helped the UICC step up to the challenge.

We're sorting out photographs to accompany this interview, and Isabel Mortara is laughing at how many seem to show her waving her arms around, betraying, she says, her Italian roots. But the truth is that you'd be hard pressed to tell what Mortara's roots are: she has an American accent, lives in Geneva, was educated at the International School and went to university in Israel to read International Relations and Soviet Studies. The outgoing executive director of the International Union Against Cancer (UICC) is truly international in upbringing as well as outlook.

As for conforming to the arm-waving, passionate, impulsive Italian stereotype, forget it. Mortara, who stepped down from the UICC at the end of August after 25 years, nine of them at the helm, is (by her own assessment) systematic and analytical. It may have been passion and family experiences of cancer that moulded her will to transform the UICC into an influential force, but it was cool logic that enabled her to do it.

When she was appointed executive director at the UICC in 2000, it was largely a Europe and North

America-orientated organisation, centred around the needs of doctors, providing support for practice and research. Mortara's interest was prevention, informing patients, fighting stigma, raising awareness and improving early detection – plus tackling the growing disparities between the developed and developing world. A female non-medic in a male doctor-dominated world, with a business rather than a health background, she came in with a new perspective. UICC needed a strategy, she thought.

The result has been an increase in UICC staff from 19 to 25, rising membership, increasing involvement from commercial partners, a quadrupling of turnover, and the World Cancer Declaration, World Cancer Day and World Cancer Campaign. Looking back, one episode just a month ago provides her with particular satisfaction about progress in early detection and access to treatment that wouldn't have happened without UICC's recent My Child Matters campaign.

"I went to Dakar in Senegal where we had a workshop bringing together all of the projects from the different countries to report on what they've



COURTESY OF UICC

entirely pain-free.

In truth, only one of Mortara's parents, her father, is Italian, but her mother, Swiss by birth, was brought up in Italy. Italian was always spoken at home, even though the family moved around a lot, as the work of her father – an obstetrician, who became a regional director for the World Health Organization, setting up schools of midwifery – took them around Asia.

With the family (she has one brother, now a neurosurgeon) eventually settling in Geneva, Mortara went

been doing, with the aim of seeing how we could transfer some success stories to other countries," says Mortara. "The Prime Minister of Senegal came to the workshop with his minister of health, and announced that treatment in Senegal would be free for all children. So you have a sense that in relatively few years – we started this in 2006 – we've made a lot of progress."

But the process of transformation hasn't been

to the International School there, where she says she consciously 'decided' on adopting an American accent in the absence of any that came naturally. Then she went to Israel for her undergraduate degree – mainly because she fell in love with the place during year-off travels. On arriving, she discovered that all the studies were conducted in Hebrew, so she spent the first year of a four-year course learning the language.

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CANCER IN THE FAMILY

Then something happened which would, unknown to her at the time, influence her career profoundly. When she was 19, her father became seriously ill with colon cancer. “He was first totally misdiagnosed here in Geneva, then we flew him to the United States where they gave him very aggressive treatment which probably prolonged his life by a month or two, but it was very painful.”

Mortara stayed with her father in the US for the six months up to his death. Then, months later, her mother developed breast cancer. She was diagnosed early, had a mastectomy, and is still living in Geneva, at the age of 88. But Mortara is dismayed, when she looks back, at how emotionally gruelling the experiences were for patient and family. She can’t forget that the American surgeon who looked after her father was a heavy smoker, or how little information he and the other doctors gave to the family. Or how she, still a teenager, was expected to sign a release form allowing surgeons to remove her mother’s breast without any explanation of what they were doing, or the risks. Or how her mother refused to talk about her cancer from the day she was diagnosed, because she was ashamed.

“I wasn’t allowed to say anything to my mother, and that was really hard, not being able to share her experience,” she says. “Having seen all that, I really felt there was a lot to be done – because even when I started working at UICC 25 years ago there was a stigma, and there still is – especially in Africa and Asia. When my father died, I realised that cancer is not just the patient, it’s the whole family. It’s a long disease, where you’re often watching someone deteriorate, and everyone is anxious – everyone needs attention.”

So looking back, what happened next sounds a bit like fate. Mortara took an MBA at the University of Geneva, and worked at a Geneva business school for 10 years recruiting students internationally. Then a headhunter picked her

out for the job of head of education at UICC, convinced that the organisation needed someone like her to put it on more of a business-like footing. He had some work to convince UICC to come round to the same point of view, but they agreed.

“I think it was a real call to action for me,” says Mortara. “I knew there was a lot to be done. And I think that the work that we did subsequently at UICC to cater for youth, and the children of cancer patients, improving understanding of cancer, encouraging people with cancer to tell their stories, drew on my own experience. Also, my experiences of nurses was so outstanding during my parents’ illness, it influenced the way we created nursing associations in developing countries and linked them with nursing associations in developed countries.”

In 2000, Mortara was appointed executive director of UICC. It was a difficult time: the balance book had been hit by two financially catastrophic congresses; the longstanding and influential secretary general had died; other richer and more powerful cancer organisations were springing up around the world, also offering conferences and dealing with developments in treatment research. It was a time to reposition.

But it would not be an easy process. Even when she had first joined UICC, Mortara had to overcome expectations that all roles should be filled by men, and felt obliged to go back to work straight after having her two children because there was no system for maternity leave. Now she was executive director, she also had to overcome expectations that leaders should be doctors.

“But I put together a strategy, and worked with the board, our president, the directors and leaders, and pushed the plan through. It’s been a long process. It takes a lot of convincing, a lot of questions, a lot of unhappy people. But, yes, I put a new structure in place, trying to get UICC back on the rails.”



GIL CORRE

A TURN TO DEVELOPING COUNTRIES

What the strategy amounted to was a complete reorientation. The four-yearly congress was made every two years to keep up with the rate of scientific advances, and its organisation brought in-house. The UICC changed its emphasis from professional education to public education, from treatment advances to prevention and early intervention, from supporting professionals to capacity building, from the developed world to the developing world.

“At that time, nobody was really dealing with developing countries,” says Mortara. “There have been a lot of new technologies and developments in cancer over the years that have not been accessible to countries with fewer resources to treat cancer. Plus, the cancer burden has been shifting to developing countries, where people are starting to adopt Western lifestyles – smoking more, eating more, exercising less. So there’s a gap that is growing exponentially, and nobody else is dealing with. The fact that we’ve started

My Child Matters. With 33 projects on childhood cancers running in 21 countries, the My Child Matters campaign is not only helping thousands of children, but also demonstrating that even poorer countries can take effective action against cancer. Here, Mortara is shown with a young patient being cared for at the paediatric cancer unit of the Aristide le Dantec hospital, Dakar, Senegal

to reach out to the less developed countries is part of a changed strategy to actually do something about it.”

The move towards prevention, particularly in the developing world, was prompted by emerging data from the WHO’s International Agency for Research on Cancer (IARC) showing that around one-third of all cancers could be prevented, and another third could be successfully treated if diagnosed early enough. It culminated in UICC’s World Cancer Campaign – a five-year programme launched in 2007 to raise awareness about the causes of cancer, and how individuals can prevent it through the choices they make.

“It made a lot of our member organisations look at

The UICC changed emphasis to public education,
capacity building and the developing world

“The members are the ones that effect change at local level – we give thrust, direction, and practical toolkits”

what they were doing in prevention, and increase their activity. The members are the ones that effect change at local level – we’re giving thrust and direction, and practical toolkits.”

But perhaps Mortara’s most controversial change of direction came with the introduction of commercial partners to UICC, to support projects that would never otherwise get off the ground due to lack of funding. She is clearly proud of the My Child Matters campaign, launched in 2005, dedicated to improving the detection of childhood cancers, particularly in the developing world, where the cure rate is shameful compared with richer countries. It is now funding 33 projects in 21 low- and middle-income countries.

But it wouldn’t have happened without drug company Sanofi-aventis. Mortara managed to get corporate social responsibility funding from them, but the UICC had never worked with a corporation before, and even with the introduction of strict guidelines, she faced significant resistance to the partnership from her board. “I failed several times to get it accepted,” she says.

“For some people, the idea of getting a large amount of money from a pharmaceutical company was just totally unacceptable. To get that one acceptance through was very difficult, but it has since become one of our most important projects.” Since then, there have also been partnerships with Pfizer and Glaxo SmithKline. The resistance, says Mortara, has largely dissipated because it’s been demonstrated that partnerships can work.

There have been other struggles too. Getting UICC’s 300 member organisations working together and in the same direction has not always been easy. “Organisations in every nation had had their own campaigns. What had never happened, before we did it, was for all these members to be engaged in the

same campaign, at the same time, sharing data, comparing information and so on. This was something potentially very valuable for the UICC. But it has been challenging, too. There’s been jockeying for position, some members wanting to be leaders, and there’s been a huge effort in reconciling that when the whole concept has been sharing and exchange. We had to persuade some organisations that they had an international responsibility to become involved, even if the issue had been dealt with already in their country.”

WORLD CANCER DECLARATION

Then there’s the World Cancer Declaration. Launched in 2006 and revised in 2008, the declaration is a call to action to substantially reduce the global cancer burden by 2020. Developed to bring the cancer crisis to the attention of policymakers worldwide, it lays down 11 targets and an action plan to reverse current trends. Mortara, who pushed for the development of the Declaration, believes it is the single most important tool to get the international community to work together to reduce the cancer burden in the coming decades.

But it’s not a universally shared view. “If everyone were working towards those 11 targets, we would probably be effective in reducing deaths and incidence of cancer. But I’m not sure all the UICC board and members agree with me. I think some still see the Declaration as a piece of paper, and say there are many other declarations around the world.”

“It does take some imagination to make it work in practical terms, and translate it into an action plan at local level. It requires funds. It requires considerable effort, and is a long-term process. But it’s important to use the Declaration to raise awareness of what needs to be done, because so many government officials, and

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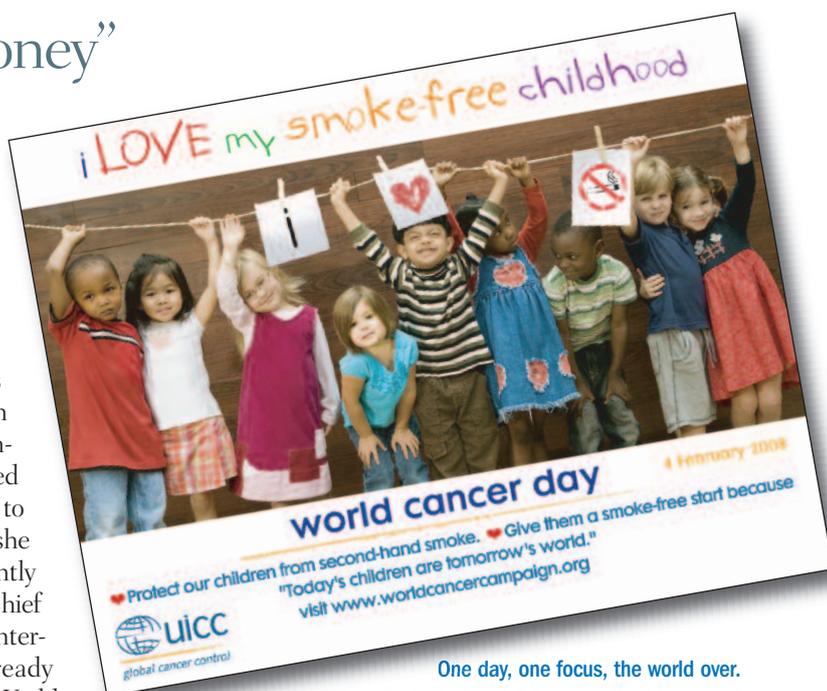
“I think it’s incredible what the not-for-profit can achieve with so little money”

even ministries of health, just don’t understand the dimensions of cancer. They don’t understand that cancer is an issue in their country. We’ve talked to governments from some African countries who were very surprised when they saw the mortality rates from cervical cancer in their country.”

She hints at a suspicion that once she has gone, the Declaration will no longer be high on the agenda. “I don’t think the Board is convinced that the Declaration can be translated into actions which will make a difference to people’s lives.” It sounds like one regret. But she may take heart from the news that her recently appointed successor, Cary Adams, formerly Chief Operating Officer of Lloyds TSB Group International Banking in London, has already announced his intention to implement the World Cancer Declaration in the coming years. Her fears may be groundless.

So why is she moving on now, with so much achieved and an agenda still to push forward? It’s simply the right time, says Mortara. Having put the UICC back on track, she is confident that her successor will move it on further, and she wants to try something new before her working years are over. Her family – her husband is a civil engineer, her daughter, 20, is studying law, and her son, 18, is finishing his International Baccalaureate – are all based in Geneva, so she has no intention of moving. They’ve always enjoyed weekends together in the mountains, skiing, cooking and playing music together. They’ll continue to be the first priority in her life.

She is considering several job offers before making a decision about the next step, and inevitably has her own ideas for new ventures, borne from the positive and negative experiences of working for so long for a non-governmental organisation. “I think it’s incredible what the not-for-profit can achieve with so little money, but it can be challenging. Decisions take a long time, people take a lot of convincing, and I think I need to work in an environment where the decision-mak-



One day, one focus, the world over. The Charter of Paris declared February 4 World Cancer Day in 2000. Mortara was instrumental in turning this day into a truly global event, together with UICC’s 300 member organisations across the world and in partnership with the WHO. Each year on World Cancer Day, the UICC launches a prevention theme with global media attention and develops toolkits to support activities with members at the local level

ing is faster and you can move forward more easily.”

“What I like doing is capacity building in organisations in the health sector, helping them to develop and play a catalytic role in society. I would like to see governments, foundations and communities provide larger-scale support for our efforts, but there is still a way to go in putting cancer onto their agendas.”

The real opportunity for furthering health issues on a global level may lie, she believes, in linking not-for-profit bodies with the corporate social responsibility programmes. It sounds as if it may well be the way ahead in Mortara’s own career too. “What I’ve seen from the corporate sector is their ability to give you the funds to get a job done. There’s a connectedness there. Exactly what it is, I don’t know!” She laughs, keeping what is probably a very good idea tight to her chest. “But I like the combination. There’s something there.”