

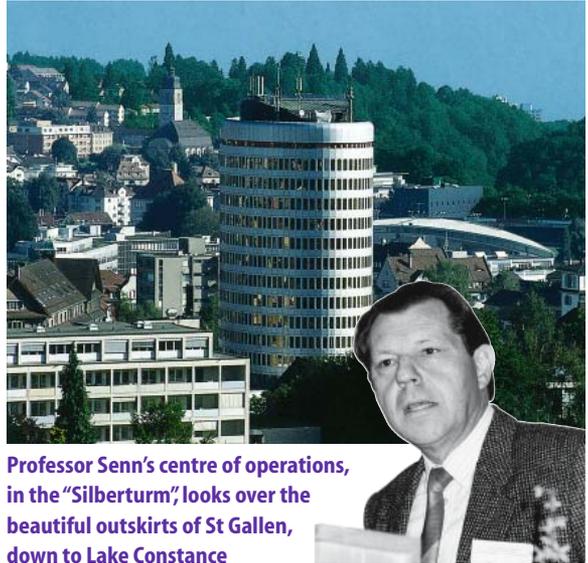
Hans-Jörg Senn: Championing Consensus

ANNA WAGSTAFF

Throughout his long career, Professor Hans-Jörg Senn of the St Gallen Tumour Detection and Prevention Centre has shown an impressive ability to keep one step ahead of the field. In 1972 he was among a small group who initiated one of the first trials of adjuvant treatment of breast cancer, despite heavy opposition from the wider medical oncology community, who thought it was crazy to give chemotherapy to healthy women. In the mid-1980s he was one of the first to recognise that the heady pace of progress in finding medical solutions to cancer was slowing down, and that it was up to oncologists to find ways to help their patients live with their disease. And today, Professor Senn's

St Gallen centre is flagging up primary and secondary prevention as the next logical priority in the major cancers. It is a record that any budding young medical oncologist might wish to emulate. And yet, arguably, the unique talent of Professor Senn lies not so much in his pioneering ideas, but in his ability to bring the medical oncology community along with him. For it was from a small meeting in St Gallen of those "crazy" trialists that the International St Gallen Guidelines – now the reference point for adjuvant breast cancer therapy over much of the Western world – were later to emerge. How did he do it? Anna Wagstaff from CancerFutures took the train to St Gallen to ask him.

CancerFutures: The St Gallen Conferences are unique in that each time they end up delivering a new consensus about the best treatment options currently available, and these effectively become the guide-



Professor Senn's centre of operations, in the "Silberturm", looks over the beautiful outskirts of St Gallen, down to Lake Constance

lines used for the next two years in hospitals and clinics around the world. How did it all start?

Hans-Jörg Senn: The St Gallen Breast Cancer meetings started with

our work in breast cancer. Back in 1972, I had just taken up my position here in the Kantonsspital St Gallen, and we wanted to start a programme of adjuvant treatment of breast cancer. We were on the very brink of the era of using drugs to improve cure rates in breast cancer, just about a year after Gianni Bonadonna in Milan and Bernie Fisher in the States started their programmes. At that time adjuvant treatment wasn't seen as innovative, it was seen as absolutely crazy, and we were heavily criticised by the medical oncologist community. We were ostracised for

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putting healthy women on chemotherapy.

Those of us who were involved in these first adjuvant breast cancer therapy trials felt that we needed to get together to exchange data and

discuss results. So in 1978, we called a gathering of trialists. There were 78 of us, and that was actually the first of the St Gallen conferences.

After a few years, we decided to repeat this conference to monitor the progress of our clinical trials. So the next conference was held in 1984, and then in 1988 and so on. The consensus process was introduced at the third meeting. The conference chairpersons, Aron Goldhirsch and Richard Gelber and myself and a few others, wanted to unite all these differing results and views. And despite the objections of medical oncologists at that time, these conferences have grown ever since. To be frank, that is not what we had intended. All we wanted at the beginning was a gathering of trialists. But we began to realise that breast cancer is not just treated by trialists, but by virtually every hospital across the world.



The 1990 Consensus Conference opened on a harmonious note, with a concert in the spectacular St Laurenzen Cathedral

CF: Medical oncology is a constantly changing field, with many leading authorities, and there will always be disagreement among them. Why do you think it is important to reach a consensus on the best treatment?

H-JS: The importance of consensus is that patients all over the world, or at least all over the Western world, where we have comparable medical systems, get the best treatment as recommended by international specialists on the basis of all the scientific facts available to us. If one centre claims to offer better treatment, you can end up with a kind of “patient tourism,” which we don’t like. The patient should get the same optimum treatment in all parts of these “comparable” systems.

CF: The requirement to reach a consensus means that the International St Gallen Guidelines necessarily err on the side of the conservative, making them perhaps slow to take on new treatments. Do you see this as a drawback?

H-JS: This is a reproach that is sometimes levelled at us. I think we are prudent. We only give out guidelines that are based on real evidence. Otherwise you risk having to retract then two years later. Two years ago we were heavily criticised for failing to reach a consensus over integrating high-dose adjuvant chemotherapy into our guidelines for treating patients at very high risk of relapse. But then one year later the South African study that had come up with strongly positive data was dis-

covered to be a scientific fraud and could not be replicated. So sometimes people who always like to be more modern can become victims of their own hopes and illusions.

That’s the reason why the International St Gallen Guidelines should be evidence-based and conservative. It is up to the national health boards, oncological societies and so on to change these guidelines, or to supplement them, if they want to.

CF: Others have tried to emulate the consensus approach, in the fields of, for instance, ovarian cancer, adjuvant treatment of myeloma and melanoma, but without the same success. Can you explain how it’s done?

H-JS: A team that tries to do it has to have international credibility. If we had tried this on our own, I don’t think we would have been successful. In our case, the link with the

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International Breast Cancer Study Group (IBCSG) was very important. Leading members, like Aron Goldhirsch from Lugano/Milan, heavily influenced the scientific content of these conferences, and he was usually one of the chairmen of our consensus meetings held at the end. The composition of the consensus panel is also utterly important – who is in and who is out. If you do not assemble the great majority of the opinion leaders, you run the risk that those you leave out will form an “anti-consensus.”



Delegates to the 1988 Consensus Conference had a chance to get to know each other at a reception in this impressive setting of the St Gallen Museum of Arts

But of course it's always a battle. When you have all these valued exponents of different ways of thinking in one panel, people like Bernard Fisher and Michael Baum, for instance, who holds some very controversial views on the issue of screening [see Masterpiece, *Cancer-Futures* vol 2 (7/8)], and you have three hours to get them all to come up with a set of guidelines they can all put their name to, it's not an easy task. Every time we have this battle at the end, and even after the end of the conference. But so far there has always been a result. We have managed to get the people to come to an agreement.

We also make an effort to create the right sort of atmosphere. We encourage delegates to explore the culture of the city and the beauty of the area, and to get to know one another on a social level. We offer the speakers the chance to spend a few days skiing. So it's not only scientific exchange and battling. I think this can help. I am certainly told that there is a certain aura around this conference.

CF: Where would you like to see the St Gallen Conferences going from here?

H-JS: When the Conferences first started, 25 years ago, mastectomy was standard, at least on this continent, and adjuvant chemotherapy was something that came after surgery, stuck on like a pigtail. Now breast-conserving "lesser" surgery is standard, and adjuvant therapy has become the main part. So things change, and we have to change accordingly. For instance, the Conference has now changed its title from Adjuvant Therapy of Breast Cancer, to Primary Therapy of Breast Cancer, to reflect an increasingly multi-model view that incorporates into the consensus everything on the treatment of early breast cancer, whether it is surgical, or radiological, or chemo- or hormone therapy.

I would like to see breast cancer prevention becoming a central focus. This is a gap in medical oncology that I have become increasingly aware of during my long period working in hospitals. While we need to find the best treatment for advanced disease and supportive care, it would, of course, be far better to avoid disease, or at least to avoid extensive disease, to discover it early and to treat it with a less traumatic impact on the patient. Here in St Gallen, we are part of the first international trials of chemoprevention of breast cancer, which involves giving chemotherapy to healthy people who genetically or through family history are at very high risk of developing cancer, in order to stop the disease developing at all, or at least delay its onset. I think this will be a big thing in the future.

CF: When you see the International St Gallen Guidelines adopted as national guidelines in many European countries, and used as the handbook for treatment in hospitals from Australia to the UK, how do you feel about your personal role in it all?

H-JS: I would be lying if I were to say I am not proud of it. It is a practical contribution that we in St Gallen have been able to offer the oncology world.

CF: Another very practical contribution of yours has been to champion the cause of the patient's quality of life. You organised the first international conference on supportive care and launched the journal *Supportive Care in Oncology*. What made you take up this issue?

H-JS: To be honest it was our nurses, particularly our head nurse Dr Agnes Glaus, who persuaded me to do something about it.

It was around the mid-1980s. I'd had the great privilege of living through the age of discovery of many new cytostatic drugs that could cure disseminated cancers such as leukaemia and lymphoma, as well as testicular cancer metastasising to the lungs, and so on. Many people were convinced that this process would go on, and we would find ways to cure everything that disseminates. But around this time, many of us began to realise that this process was beginning to plateau out, and that we had a lot of patients for whom treatment would remain palliative.



Dr Agnes Glaus, head nurse at the St Gallen Tumour Centre, was one of the first to argue the case for supportive care

We could, perhaps, keep them in remission, but there were side-effects. And so the balance between effects

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and side effects was coming increasingly into question.

CF: So what did you do?

H-JS: In February 1987 we assembled all the people we could find in the literature who treated and managed pain, or nausea and vomiting, or infections – all the aspects of supportive care which make the patient's life more agreeable – and we called the first meeting of Supportive Care in Cancer Patients. There were more than 700 people, about half of them nurses – specialist nurses, academically trained nurses, from America, Australia, about 75 countries in all. And that was the start of “supportive care” at the international level.

In a way we were victims of our own success, because within one year there were two more first international meetings on supportive care in cancer, which were virtual copies of ours. One of these was called by an American conference organiser, who took our name and branded it for themselves. That's why we ended up calling ourselves the Multinational Association of Supportive Care in Cancer (MASCC).

The big mistake we made was that we did not create a society at that initial meeting, because, apart from problems caused by people trying to copy us, we ended up losing ground to the palliative care movement, which was focusing attention almost exclusively on pain, whereas we were trying to draw attention to the need to treat the whole range of disease symptoms, such as infectious complications, anaemia and nausea and vomiting. Happily, over the years, many of the differences between the palliative care movement, with its emphasis on taking incurable patients out of treatment, and our vision of supportive care within a treatment setting, have lessened.

CF: What progress has been made in supportive care since that first meeting?

H-JS: From the initial meeting we set up a journal, Supportive Care in Cancer, dedicated to exploring the new field of supportive care and stimulating thinking about how we can benefit patients. I think we managed to get the issue onto the agenda, because today supportive care is no longer only talked about by us, but it is discussed at the major medical oncology conferences.

Important progress has also been made in new treatments. The Italian Society of Medical Oncology, for instance, has done great work on anti-emetics. Another important development is the injection of growth factors to stimulate erythropoiesis or leukopoiesis in the bone marrow, curing anaemia, or leukopaenia, or infection. And this of course means that industry is starting to take more of an interest, and is bringing more funding into this aspect of cancer care, because supportive care now represents a market for them. Previously, lack of funding was a real problem, and we struggled initially to find enough backing to launch the journal.

CF: At what level do you see pressure for change being most effective? Would European Guidelines on supportive care encourage change in health systems that have been slower to take supportive care on board?

H-JS: The change needs to come from a national level, because, unlike breast cancer, which poses a more technical problem, supportive care has a lot of psychosocial and emotional involvement and social and cultural differences play a much bigger role. For instance, "truth telling" is different in southern Europe than in northern Europe. As the editor of Supportive Care in Cancer, every third month or so I get a paper from Turkey or Greece or from another southern country that tells us that 79% or 85% of the population would not like to be told if they had a bad prognosis. This is completely contrary to what is going on here

and in the US. We don't understand each other on this level. We cannot copy each other's systems.

There are also legal differences. Pain treatment, for example, will vary because there are still countries even in Europe where all opiates remain illegal. Euthanasia is another issue that differs in both the cultural and the legal approach from country to country. So I think European Guidelines could be effective, but only if they are drawn up by panels in which all the countries are truly represented, which is often not the case.

CF: Where would you like to see the supportive care movement going?

H-JS: We would like to see more medical oncologists and oncology nurses taking up the issues, and to see supportive care featuring more prominently in their meetings. I think there remains a certain passive resistance – perhaps because it is still confused with the early palliative care movement, so some people feel there is a contradiction between supportive care and the primary task of curing patients, which there is not. It's all part of the same holistic approach. Unfortunately, the system changes slowly. I would like to see much faster progress in getting medical oncologists to embrace the concept of supportive care.

CF: Finally, I'd like to address the question of language and communication. You were instrumental in setting up the first German-language courses for the European School of Oncology (ESO) – the Deutsch-

sprachiges Programm. What prompted this?

H-JS: When I'm teaching, I've found that English is all very well when you are dealing with purely scientific, medical subjects, but you run into problems when you want to discuss personal, emotional, or spiritual issues. This can only be done in

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your mother tongue. Also English is little use when teaching oncology nurses, because, at least in continental Europe, nurses are vocationally trained, and their English is often not good enough. It was an ESO conference in Vienna that finally convinced me of the need to run some courses in German. Almost all of the 75 nurses and physicians attending were German speakers, and yet there we were, trying to conduct a discussion in English. It was not only impossible, it was ridiculous.

So about seven years ago we started introducing the more practical courses – on social aspects of care, palliative care, supportive care



and nursing courses – in German. We were not the first – there were already ESO courses running in French and Spanish – but we are now the most flourishing language section of ESO. We run 15 or 16 courses every year, and they are very popular.

CF: Language continues to be a barrier to working at a pan-European level, and the picture is becoming more complicated as more countries join the European Union. Do you think more language programmes could be a solution for other language groups?

H-JS: Not necessarily. First of all, programmes have to be efficient and

economically viable, because they take time and money to organise. It works in German, because there are more than 100 million people in Europe who speak this language – more than French and Spanish put together. But you couldn't do the same, for instance, for Bulgarian or Romanian. The issue of quality is also crucial. ESO courses are based on the most up-to-date evidence-based knowledge, and all teaching staff are highly regarded within medical oncology. We don't want that to be jeopardised by further language diversification. The English language courses will always remain at the core of the ESO curriculum; while the other language programmes are important, they can play only a supplementary role.