

A lesson in getting old *by Pierre Mertens*

An expelled Uzbek killed 4 innocent people with a truck when driving through a shopping street. One of them was a young Belgian woman. Sweden is slowly recovering from this disturbing drama. But they emerged stronger. Nobody misused this event to blame foreigners. No politician stood up to blame the others.

Last year Björn Ründström celebrated his 90th birthday and left his two large houses on a lake in central Sweden for a small apartment in Uppsala. Seven months after this move I visited him for the first time. It is a beautiful and light place, with a large terrace overlooking a park. He has been an art collector and had to select carefully what he could take with him. He selected items for quality and memories. Surrounded by these objects of the past he is now organising this new period of his life.



Pierre Mertens and Björn Rundström, a selfie made by two old IFHSB friends

He was founding president of IFHSB, the International Federation for Spina Bifida and Hydrocephalus, now known as IF. IF started in the same year that we began the Flemish association for Spina Bifida in Belgium.

I first met Björn at the Malaga IF conference in 1983. I saw him as a very old grey man and called him 'the mummy.' He was at that time much younger than I am now. He called me 'the boy'. By working with him he proved to be a nice man with a good sense of humour.

We have known each other for 34 years and we worked together for 23 years in this organisation. He left the IF board in 1995 and I stepped down in 2013. Two retired presidents share a great deal of history, but I knew very little about the beginnings of IF. I decided to interview him. This proved to be a lesson in getting old.

Who decided to start IF?

BR: In 1977 I was sent by RBU to Britain to represent Sweden at the Exhibition for technical aids and whilst in the UK we went to a Cerebral Palsy (CP) meeting in London. At that time mothers of children with CP in Sweden were meeting and had a lot of fun, but more importantly, they learned a great deal from each other.

He stands up and goes to his little office. He returns with a bunch of IF magazines and puts them on the table.

BR: Everything is here. You should read all of this.



Björn has cooked excellent meals for me

When we started there were so many CP children, many more than spina bifida. Before Holter invented the shunt in 1953 most children with Spina Bifida died but the CP children survived. Now ... children with Spina Bifida survived too, so their parents set up their own organisations. The UK spina bifida organisation ASBAH (now named ... SHINE) was created in 1966. In London I met their director Moyna Gilbertson.

The idea of an international federation for spina bifida was born at that meeting and adopted by RBU who took the lead in this initiative.

As father of a daughter who had spina bifida RBU asked me to look for other spina bifida organisations. I travelled all over Europe and brought together representatives of organisations from nearly 20 countries at the first Spina bifida conference in 1979 in Stockholm.

We invited the leading professionals, including Dr Lorber and other doctors, and famous professors gave lectures. It generated great enthusiasm and the delegates decided to create IF.

I was appointed to lead an interim board with Moyna from England, and Peter Frosio from Switzerland, Oriol Tuni from Spain and Ineke Meyer from the Netherlands. With Michael Nevil from the Irish association we organised a second meeting in 1981 in Dublin and IFHSB was established officially. It is dangerous to mention names. You always forget valuable people. But those were the avant-garde. After this came others. Moyna was Vice President and when she stepped down Teresa Cole replaced her and became your first Vice President.



Björn Rundström when visiting me in Antwerp

In 1983 at the third IF conference we met for the first time. You looked very concerned. Was there a problem?

BR: There were some conflicts between the Barcelona and Madrid associations. But this is political. In these organisations politics can play a role. These organisations have all their own history. Some are big and run by professionals; others are small and run by one or two parents.

The conference room was some way from our hotel. This was not easy as we had to go by bus from one place to another.

The conference was important because we asked all countries to complete a questionnaire which was to be the basis for our further work. I took it to work on, while you had fun in the swimming pool.

What came out of this questionnaire?

BR: Most organisations had problems to get their children integrated in schools. It was felt that our children did not have the same opportunities in society for employment and integration and there was a great need for updating of on-going research.

At that time a lot still went wrong for our children. We needed the most recent information on new techniques and possibilities.

In which of these fields were you the most successful?

BR: The situation is different in most countries. In Sweden I believe we made great progress in inclusion and medical follow-up. Children and adults with spina bifida have a much better quality of life nowadays.

We learned a lot from what other countries achieved. Exchange of knowledge and ideas was one of the most important benefits of IFHSB.

Most of the IFHSB members were European plus Japan and Australia.

But we were also focussing on Hydrocephalus not only spina bifida.

Hydrocephalus was rare in the North and despite the success of the shunt the spina bifida was still a problem. In Africa we saw the problems hydrocephalus causes.



Gerd and Eva Ründström long ago

I was not successful in America, China or India. We had no money at all. Everything was done at my kitchen table. No staff, no office, only a small group of international friends.

That's what I wanted to ask, who paid the bill at that time?

BR: We received a small budget from RBU. 30-40 000 SKR was our yearly budget for travelling and administration. The member countries paid a small contribution and of course I paid a lot myself, as you did too. I was still working as a teacher and my school was very supportive in allowing me to travel.

Where was the official IFHSB address in the beginning?

BR: For many years the office was hosted at RBU and I even got a small desk when preparing the second Stockholm conference. We also received good support with administration and staff from ASBAH.

From Stockholm we joined the International Disability Centre in Geneva and from there you moved it to Brussels where it still remains.

How long were you president and what is your main achievement?

BR: 17 years. I stepped down in 1995 when you took over. I was 70 years old but I continued to help IF with the magazine till 2001. But the biggest success is that what I started is still alive and active.



You started in Africa. How did this come about?

BR: When I was in New York to lobby for consultative status from the social council of United Nations they asked what we were doing in developing countries. Indeed at that time we were an organisation of the North.

But the biggest success is that what I started is still alive and active.

In 1992 Mr. Ashihundu, the chairperson of the Kenyan disability movement visited Stockholm and I was able to meet with him.

He suggested that we organise a workshop at the Rehabilitation International (RI) conference in Nairobi in 1993. And so we did, although we had no money to register. But we were on the programme and had a successful workshop with African parents, surgeons and NGO's. You even paid for your flight by selling a painting from a Polish artist.

How was the African experience for you?

BR: We realised that we knew so much and had useful information to help African parents. We invited the neurosurgeons Dr. Mwang'ombe, who was present at the workshop, to our next IF conference in Deinze (B) and all our IF members were enthusiastic to help our peers in Africa. At the same workshop was Sister Marcella from Lilianefonds who had a network throughout Kenya to assist disabled children and she asked for our help. This was the real start of our African journey. And then you took over.

That was in 1995 .

BR: Yes, in Sidney there were a lot of people and Fiona Stanley really put folic acid on our agenda. Fortification of flour with folic acid opened the door for successful primary prevention. After this conference I invited Fiona to Stockholm and she came. After the conference I went with my wife Elisabeth to one of these islands with all the noisy but colourful birds.

During the 60 years you have been active in the disability movement what changes have you seen.

BR: You know my Eva had an accident at school and broke her chin and developed additional disabilities. Even though she is very disabled she is able to live a rather independent life. Probably Sweden is one of the few countries in the world that

makes this possible. She gets personal assistants, transport is arranged and medical care made it possible for her to reach the age of 60 and arrange her life in an acceptable way.

The outcome for children with spina bifida has never been so good as now. Fewer children are born with spina bifida as a result of prenatal selection and termination of pregnancy. This is not a solution, especially because in the Global South spina bifida is still not uncommon. This situation alarmed many of our organisations for spina bifida in Global North as they now rarely see new cases of spina bifida. This is a sad evolution. Will parents still have the choice these days to fight for the lives of their children? I hope so.

In Sweden a new association for adults with spina bifida has been created. They are the largest group now. Elderly people with Spina Bifida face special medical problems. They need full attention.

What would you like to see in the future? What do you wish for those who are active now in the IF network.

BR: More attention and initiatives for the large group of adults and elderly people with Spina Bifida similar to the new group which Sweden is trying to establish. The many untreated children with Hydrocephalus still present big problems. IF and Child-Help are working hard, but more must be done. It is unacceptable that in 2017 there are so many children not receiving the treatment they deserve.

During my days in Uppsala Björn has cooked excellent meals for me. Waiting for dinner I started reading the magazines Björn made. 3 bulletins and 35 Back-UPs. The look improved and the printing became more professional and attractive. But from the start of IFHSB these documents contain all the history of this special movement of these very special people. When I read it through, my own story with Liesje and within IF appears like a movie of a big part of my life. It probably was the right decision to invest in Internet and website communication and cease publication of the printed magazine. But what will survive of the digital information after 30 years? The annual reports were printed of course, but those also became digital. Everything disappears. Maybe I am getting old. Shall I ask Björn to teach me more about getting old? Getting old is about enjoying good memories and accepting that we are all only passengers in an ever changing world.