

Historical retrospectives of the EULAR Allied Health Professionals

Two decades of engagement by Ulla Nordenskiöld

One could say that it all started in Sydney 1985 at a congress organized by the International League Against Rheumatism (ILAR). Health professionals from all over the world participated in this congress, and I was working as the chairman in a workshop under the title: *“Joint protection: fact or fiction”*. This was the first international occasion in which I was personally in contact with other allied health professionals who shared the same interest in rheumatology. During the congress, we had the opportunity to gather up an informal network meeting which involved enthusiastic professionals wanting to keep in touch also in the future.

Two years later in Athens, I presented my first abstract in a EULAR Congress. It was about *“Soft wrist orthoses effects on pain and gripping power in women with rheumatoid arthritis”*. In the beginning, we had to send our abstracts to the same scientific review as the physicians did. When our abstracts were accepted, we presented them along with the same scientific programme. For this reason, the physicians had to listen and also take part in the discussion on our results. This was very important in order to highlight the significance of the health professionals' work; their special methods, interventions and outcomes measurements, also from the patients' perspective.

In Athens in 1987, a British nurse **Vicky Stephenson** arranged a new meeting for some 30 health professionals. This time, we voted on establishing our own group in EULAR for the Allied Health Professionals (AHP). The elected health professionals for the group, including Vicky Stephenson and me, were occupational therapist Ingrid Due Pedersen from Denmark, pharmacist Angelica Kruse Jensen from Norway, and social worker Willy Peters from Belgium. These members formed the first official and active working group of health professionals in EULAR. Vicky Stephenson was very determined to elevate our group into EULAR's actual Standing Committee. Ingrid Due Pedersen who already was involved in the EULAR Social League was as well a very big help in promoting the health professionals. Also from the very beginning, **Fred Wyss**, Executive Director of EULAR, gave valuable support to our efforts of building a Committee.

The seventh committee

The new Standing Committee of Health Professionals in Rheumatology was formally founded by EULAR in September 1989, and we became the seventh committee under the EULAR Executive Committee. Each European member country could propose a participant to the Standing Committee. In my case, the Swedish Rheumatism Association which was already a member of the EULAR Social League proposed me into the Committee. **Vicky Stephenson** was elected to be our first chairman. **Willy Peters** started as vice chairman and **Ingrid Due Pedersen**, **Angelica Kruse Jensen** and **I** were the first Committee members. The aims of the Committee were to disseminate information and experiences, plan and organize AHP meetings alongside with EULAR congresses, and to work towards a greater awareness of AHP's work in scientific articles and symposia. More members from other European countries were slowly participating in our AHP Meetings.

In Amsterdam in 1995, British physiotherapist **Nora Price** was elected the next chairman. The following year, EULAR offered assistance to the Committee with the help of secretary **Sophie Edwards** from the British Society of Rheumatology. Thanks to this extra help, the Committee became more active and things began to happen. The new objectives for the committee comprised also encouraging the establishment of local AHP organizations in different countries and promoting the work of the Rheumatology Action for Eastern Europe. There were discussions on developing special teaching courses of which I will tell more about later in this newsletter.

In the beginning, the congresses were only held every fourth year but at the Vienna symposium in 1997, it was decided that there will be regular meetings for Health Professionals every second year. This made the decision making process more effective. This, of course, was very good news for us. Later on in 1999, the Allied Health Professionals had, for the first time, a full five day programme, at the Glasgow Congress. The programme was extremely popular, and 369 AHP delegates participated in it.

Turning to the millennium

In 2000, at the first Annual European Congress held in Nice, nurse **Jana Korandova** from Prague was nominated our first vice president. The most important tasks of the vice president are to improve communication between allied health professionals and to organize AHP sessions during the congresses with topics which would be beneficial to all professionals. The vice president has a seat on the Executive and the Scientific Committees in EULAR.

Also at the Nice congress, our first AHP Newsletter was introduced to the public. It was then that I started to act as the editor. The AHP Newsletter reports objectives of the committee, highlights news from the chairman and vice president, releases information about activities and views from the members. We decided to publish a spring and an autumn issue of the Newsletter every year and to send them to health professionals in all member countries. This we have done ever since.

In Prague 2001, we began to organize **Round Table Discussions** giving all health professionals the opportunity to discuss and exchange experiences and ideas for the future. The discussions formed also a forum for obtaining information about the ongoing activities in national organizations and for finding out the main research needs of health professionals. As a result of the feedback given in the round table discussions, EULAR decided to emphasize the need for a strategic review of AHP's activities. The goal was to better understand the demands of the members, as well as to clarify the role and aims of the committee. A review meeting with a great deal of hard work took place with six volunteers in London in the same year.

In addition, in 2001, EULAR had agreed to support travel bursaries and educational visits for AHP's and, next year, they also agreed to fund **research projects**. These new "privileges" from EULAR were a large step forward for us.

The first roadmap

Our Committee was the first in EULAR to have a Strategic plan which was announced in Stockholm in 2002. The Strategic plan 2002-2005 comprised five key aims. The aims were promoting high quality evidence based practice in interventions to people with rheumatic diseases, promoting the unique role of health professionals within the multidisciplinary team including clinicians and people with rheumatic diseases, supporting health professionals' work and their national organizations and network in Europe, facilitating the sharing of information, skills and resources between health professionals in Europe and to give health professionals a voice through a strong, representative and effective Committee.

The advancing of the development in multidisciplinary research of the health professionals continued to be one of the main focuses in the Committee as well as encouraging health professionals to make educational visits. Our major challenge was still, however, to increase the participation of Eastern European countries and to develop our network there. So far, our committee had representation from seven different professions from nineteen European countries but, unfortunately, 24 countries were still not represented.

In 2002, Jana Korandova retired after a very demanding period of work and physiotherapist **Jill Lloyd** from United Kingdom was elected the second vice president. A year later, in 2003, at the Lisbon Congress, Nora Price retired after eight very successful years, and a Finnish psychologist **Jaana Hirvonen** was elected as our fourth chairman. In the congress, we had three joint congress sessions together with the scientific programme and the Social league which discussed the following topics: socio-economic challenges, achieving best services, and assessment in quality of life.

In Vienna in 2005, Jill Lloyd ended her term after four respectable years leaving behind a growing and much stronger committee. Also Sophie Edwards left us after nine years of hard work. Our third vice president **Peter Oesch**, a physiotherapist from Switzerland, was elected. He proposed a new submission process for the abstracts. Also in 2005, HP's working group presented a multidisciplinary action plan to EULAR's Executive Committee.

Towards today

In Amsterdam in 2006, Jaana Hirvonen reported the results of the updated Strategic Plan. The updating process of the strategic plan was started with a Delphi analysis in which participants were asked to define the three most important tasks for the committee. Nineteen health professionals from Czech Republic, Denmark, Finland, Hungary, Netherlands, Norway, Poland, Slovenia, Sweden, Switzerland, and UK participated and suggested 70 tasks. The most agreed task was "to increase knowledge of allied health professionals from different countries concerning existence, targets and work of EULAR APHs". The next highly agreed task was "to facilitate education, research and best practice throughout Europe, particularly in those countries where health professionals are struggling".

The poster session was now organized according to the different professions that made it easier for researchers from other countries to meet and exchange information. Also, a special scientific

meeting with working groups for research and education were established consisting of co-opted members as well as standing committee members. It was proposed that national AHP organizations could apply for a membership in EULAR. For now, only the Associations from Switzerland and United Kingdom have been members.

In 2007 in Barcelona, Jaana Hirvonen's term in office came to an end after four years of very hard and exciting work, and physiotherapist **John Verhoef** from the Netherlands was elected as the fifth chairman of our Committee. For the first time, we have a third member in the EULAR's scientific committee, a British nurse **Jackie Hill**. We were very happy about this.

Our joint sessions in the year 2007 had discussions about patient education and empowerment, how new practice can be implemented and other methodological issues. As in the very beginning in 1985 in Sydney, I was the chairman for a workshop *Joint Protection – fact or fiction*, in 2007 I was the chairman for the session: *Patient education and empowerment. Back to the basics!*

Scientific work: International Symposia for Health Professionals

In the very beginning, we received much help for our scientific work from supportive physicians such as the Professors **Jan Dequecker** from Belgium, **Hans Rasker** from the Netherlands, **Howard Bird** and **Ian Haslock** from U.K., and **Tore K Kvien** from Norway. They arranged five international symposia on multidisciplinary teamwork and patient education in 1986 to 1996, twice in Pellenberg-Leuven and once in Enschede, in Leeds, and in Lillehammer. The idea was just to bring all the health professionals and researchers in the field of rheumatology together. The symposia, involved invited speakers from the USA: **T. Pincus**, **L. Callahan**, **F. Wolfe**, and **K. Lorig** as well as **M. Brattström** from Sweden and other participants who were chosen on the basis of submitted abstracts.

EULAR Health professional teaching and practice courses

Anne Bos, a nurse from the Netherlands was our first educational coordinator. One of the objectives for our Committee is to co-operate with the Rheumatology Action for Eastern Europe. Together, we have organized and developed different teaching courses, for instance, in 1998, we had a course in Kaunas, Lithuania, with the help of Dr. **Margarita Pileckyte** and in 1999, we had another course in the city of Brno in the Czech Republic with **Jana Korandova**. The courses lasted for 2-3 days. In 2000, we continued organizing the courses in the Polish city of Warsaw, with the help of **Elzbieta Bobiatynska** and the next year, in the Hungarian capital, Budapest, with **Edina Sziraki**. The courses consisted of rehabilitation, patient education, spa treatment, hydrotherapy, splint-treatment, and other care programmes. The courses were successful and met with enthusiasm. However, we came to the conclusion that it is important to make an estimation of the situation of each country before organizing a course there as regards the political, economical, and the general health care situation.

The patient education material written in Swedish and called "Joint protection – for active living" has been translated into English, Czech by Jana Korandova, and into Russian and Lithuanian. This material has been used in all the teaching courses. The main idea of the teaching process is

adapting the pedagogical dialogue model which emphasizes the importance of Knowledge, Inspiration (Emotion), and Action (Behaviour). This cognitive triangle illustrates the value of meeting others in a similar situation through group education. The study material consists of a course booklet to the patients and a guide to the health professionals.

I hope that the upcoming congresses and future work will bring for new scientific findings the health professionals to stimulate discussions on research and new evidence based interventions, fruitful dialogue as well as a new, deeper connection between researchers, clinicians, and patients.

Ulla Nordenskiöld

The first editor of the AHP newsletter