

Paediatric Oncology in Europe: from national activities to pan-European research approaches. The case of NOPHO

Marit Hellebostad
Secretary General of NOPHO

The Nordic countries (Norway, Sweden, Denmark, Finland and Iceland) have a long tradition of research collaboration, which dates back to the early 20th century. To be even more integrated at the European level, NOPHO joined SIOPE in 2013 and all NOPHO's members have become individual members of SIOPE, with 126 full members and other affiliated members. Today NOPHO and SIOPE are close partners and, together, they aim to increase both the cure rate and the quality-of-life of childhood cancer patients in Europe.

The Nordic countries (Norway, Sweden, Denmark, Finland and Iceland) have a long tradition of research collaboration. The Nordic Paediatric Society was founded already in 1916, and the first Nordic paediatric conference was arranged in 1919. After the Second World War, several Nordic paediatricians showed a special interest in paediatric haematology, particularly focusing on iron deficiency and other anaemias, and in 1968 the common interest resulted in the formation of an informal **Nordic club of paediatric haematology**. The club had no formal membership, no Board, no fee and no Statutes: the aims were to create a forum for scientific discussion and collaboration, to build friendships and to give young paediatricians the opportunity to present their research within a friendly setting. The club arranged yearly scientific meetings, alternating between the countries. During the first years the main focus was on benign haematology, which gradually shifted towards leukaemia following the improvement in leukaemia treatment. As a consequence a Nordic paediatric leukaemia working group was established in 1980. Since the Nordic countries are characterised by a small population scattered in a large geographical area (approximately 20-25 million people in all countries together), the main goal at this stage was to harmonise treatment and secure that all Nordic children suffering from leukaemia would receive optimal therapy wherever they lived.



In 1980 a Nordic collaboration in paediatric oncology (including paediatricians, paediatric surgeons and radiotherapists) was created, and the two groups soon joined forces and formed the **Nordic society of paediatric haematology and oncology** – NOPHO – which was formally established in 1984. Since then, our Society has grown steadily, and as of December 2013 there were 464 NOPHO members. The organisational model has been partly centralised, partly decentralised because of the special geographic conditions in our countries, and the success has been dependent on a very close

collaboration between hospitals within each country and among the Nordic countries.

The Nordic collaboration within NOPHO has proved extremely successful. The natural starting point was the creation of a population-based registration of all Nordic children with leukaemia and solid tumours - facilitated by the fact that all these countries already had complete population-based national cancer registries since the early '50s – which proved to be essential for epidemiologic studies. The collaboration soon evolved into the creation of common leukaemia treatment protocols: the first common NOPHO protocol was NOPHO AML 1984, and from 1992 NOPHO also has had common ALL protocols. The registration has been 100 % and, because of the stability of the population, the follow-up has been close to 100% as well and the treatment results for leukaemia have steadily improved through the decades. NOPHO has joined international treatment protocols as concerns solid tumours. There are more than 20 working groups established today within NOPHO, permanent or temporary depending on the matters of interest at the moment.

To be even more integrated in European research collaborations in this field, **NOPHO has joined SIOPE in 2013**, and all NOPHO members have become individual members of SIOPE, with 126 full members and other affiliated members. NOPHO also belongs to the I-BFM group for research and clinical care in paediatric leukaemias. Today NOPHO and SIOPE are close partners and, through the pan-European integration of research, care and education, aim to increase both the cure rate and the quality-of-life of childhood cancer patients in Europe.

One important task for NOPHO has been and still is to educate young paediatricians in haematology/oncology.

Since paediatric haematology/oncology is not approved as a separate subspecialty in all Nordic countries, NOPHO has arranged specialised educational courses in paediatric haemato-oncology since 2000, and we are about to finish the 5th round of courses which will take place in Malmö in March 2014. A few places have been reserved for Baltic



participants, NOPHO members have also participated in arranging educational courses in the Baltic countries and eventually members from the Baltic countries have joined NOPHO as associated members and participate in NOPHO's leukaemia protocols.

The NOPHO collaboration has resulted in an increasing amount of research. From the epidemiological studies of the beginning, our research later also encompassed clinical trials and various other studies (biological, pharmacological, late effects' studies, etc.). The main focus has been on leukaemia. Other

important research fields are neuroblastoma, CNS tumours, late effects' studies and ITP.

The success of the NOPHO collaboration has served as a model for Nordic collaboration also among adult haematologists/oncologists, and the last NOPHO ALL protocol (NOPHO ALL-2008) includes young adults up to 45 years.

The **objectives for the future** are to continue our good cooperation for the benefit of all children with malignant diseases. We want to develop our research and our protocols further. Our combined centralised/decentralised model for organisation has proved to work rather well, but as new treatment modalities develop some treatments may have to be centralised to only one or a few centres within the Nordic countries. The close collaboration within NOPHO is a solid fundament for such a centralisation, and we also want to continue our contribution to a European and global effort to give all children with cancer a broader and equal access to high-quality treatment, which is a work SIOPE and SIOPE Europe have been jointly doing for a long time.

More information

[NOPHO website](#)

[SIOPE membership](#)