

Welcome to the first issue of *Cleft Connect*, the newsletter of the European Network of Cleft Support Groups. The first meeting of the Network was held in June 2001, the last being held in Bergen, Norway, in April 2006. The next meeting is scheduled for Utrecht in the Netherlands in November 2007. Currently the Network is involving itself in initiatives aimed at improving cleft care in Eastern Europe, and by sharing amongst its members the experiences and knowledge gained by the respective support groups, it is hoped that each group and those they serve may benefit in some small way from this collaboration. So onwards and upwards!

This first newsletter includes articles from a number of the participating countries, and is designed to give a flavour of the diversity and commonality of issues and concerns that support groups are involved with.

GERMANY

A personal story: Robin

A week before my due date I was admitted to hospital because of a complication in my pregnancy. Labour was induced. When the contractions started, my baby's heartbeat slowed down and I had to have a Caesarean section. All my hopes for a positive birth experience had disappeared but our Robin was born. It was May 26th, 2004, the time 9:10.

After the birth my midwife told me that my child had a bilateral cleft lip and palate before she briefly showed me my child. I felt lousy and was physically sick several times. I was totally

shocked. Robin was immediately brought to the premature ward. My husband waited for me in front of the operating room. He was very composed and gave me strength again. When I had overcome the first shock, my husband hurried to our baby and later brought me photographs he took of our new baby. I was extremely worried that I might not be able to love our child, but my husband immediately fell in love with him.



In the evening the paediatrician came in and told us that our Robin would have to be moved to a children's hospital some 130 kms away where they specialised in treating babies born with a cleft. Up to this point I hadn't as of yet held my baby in my arms because I was confined to my bed! It was like a nightmare and I wanted it to end! My husband was then allowed to bring me our newborn baby. So I first meet my child nine hours after birth. I loved him immediately!

The cleft didn't look as bad in real life as in the pictures. Robin was fed via a tube through his nose. I had only one thought: my body had not functioned correctly during the pregnancy. I had done this to my baby!

On day two Robin were moved to the other children's hospital, which was so far away. My husband followed the ambulance in our own car. When he came back in the evening, he had a lot of news for me. Impressions were made to fit in

a plastic plate on his palate.

My husband and our seven year old son commuted daily between Robin, me and our home until I left the maternity hospital. So I finally saw my baby again five days after giving birth and I stayed with him at the children's clinic.



By the time Robin was eight days old I could manage by myself to remove the plastic plate, clean it, put it back again, feeding Robin with the 'Playtex' bottle and handle the stripes correctly, so that we could go home. Feeding was very time-consuming because Robin never drank more than 20-50 ml in one go. I eventually gave up expressing milk and changed to formula.

Another difficulty was the quest for a competent paediatrician. We were looking for answers to so many questions, but the doctors knew less than we did about this condition. At this time we contacted the support group Selbsthilfevereinigung für Lippen-Gaumen-Fehlbildungen e.V. where we met other parents. We visited three different cleft surgeons and after careful and difficult consideration we decided on one.

When Robin was five months old he had surgery during which his hard and soft palate was closed, ear tubes implanted and his nasal septum and nostrils were constructed. After the four-hour-surgery Robin was fed via tube for four days. Then I was allowed to feed him with a spoon. This was very difficult, caused by early experiences before surgery. He never wanted to eat with a spoon because the food would go into his nose and he would not be able to breathe properly.

After one and a half weeks he was allowed to drink from his Playtex bottle again. The teats however rubbed against his stitches, so he would only drink one bottle of milk in the morning and one in the evening. When the stitches were removed, he quickly regained his appetite and made up for lost time. Regarding his growth and development, Robin also made a great leap forward.

By the time he had his second operation at the age of eight months; Robin was able to crawl and pull himself up. He laughed a lot and was a very friendly child who fascinated people with his wide blue eyes.

During a further five-hour-surgery Robin had his lip closed and his nose and maxilla were also operated on. Three days after surgery we were able to feed him with the bottle and spoon, so the nasal tube through his nose was dispensed with. The affected parts were no longer swollen and we had a better-looking child.

Unfortunately Robin caught a stomach infection one day before the anaesthetic was due to be administered and the stitches removed. So all was delayed for two days. However the result was really great!



At home we discovered that our Robin got his first tooth on the right upper jaw during his hospital stay. We don't know whether the new tooth, the surgery, the infection or the child stay at the clinic were responsible for three sleepless weeks? We hope that the worst time in Robin's life lies behind us and that things will start looking better for the future. Now we are focusing on speech therapy.

Silke

Reproduced for the German association's magazine 'Gesichter' 2/2005.

About the German support group:
Selbsthilfevereinigung für Lippen-Gaumen-Fehlbildungen e.V. -Wolfgang Rosenthal
Gesellschaft was formed to provide support for those with, and affected by cleft lip and palate (CLP). And to promote knowledge about CLP and treatment possibilities. It provides help to patients hoping to get in touch with other families.
Website: <http://www.lkg-selbsthilfe.de/>

IRELAND

This article originally appeared in the Cleft Lip and Palate Association of Ireland's Winter 2004 Newsletter.

An Adult Returning for Cleft Treatment (October 2004)

My name is Sean Ó Donoghue. I was born with a bilateral cleft of the lip and palate in 1972. I was treated for the cleft under a consultant at the former Dr. Steeven's Hospital up until 1988 where I then received a bone graft. There still remained a fistula (hole) that was covered 'temporarily' by a false denture.

After Dr. Steeven's hospital closed in 1988 I was moved to St. James's Hospital for further consultation. However I fell out the system after this either through lack of interest or more likely exhaustion on my part, and also at the time there was major upheaval in the health service, which did not help.

I continued to maintain my upper teeth over the years as much as possible but it became much more difficult as I got older. It was always my intention to complete the treatment begun in 1972 and which stopped without completion in 1988.

Treatment Revisited

Early in 2004 I finally decided it was time to seek further treatment and have the fistula closed in my palate. I had been wearing the same

retainer since 1988, to which I attribute damage over a period of time to my upper teeth and gums.

It was in early March 2004 that I started investigating how I would re-enter the system. My first contact began when a search of the Internet led to the Cleft Lip and Palate Association of Ireland's website; from here I made several contacts and by the end of March 2004, as a result of a few e-mails and telephone calls I was given an appointment for the Cleft Clinic on the second Wednesday of June 2004 at St. James's Hospital, Dublin.

Like anyone, I had many questions and fears. The fact of being an adult in my early 30s left me wondering was it now too late to complete my treatment. This concern was soon allayed on meeting with the Cleft Team. I was put at ease and from then on knew I was under the care of a team of very efficient, committed and highly skilled medical professionals.

It's now almost November 2004 and much has happened since my first appointment in June at the Cleft Clinic. The procedure to repair the fistula was completed on the 27 August 2004. With almost a four-night stay in St. James's Hospital I had the fistula closed in my palate and the temporary denture is now no more (strange feeling really after years of having to remove the denture each night before going to bed). A bone graft and tissue realignment achieved this.

How the bone graft procedure has changed over the past 16 years! The procedure in 1988 resulted in a scar running about 6 inches (15cms) down the left side of my hip and it took days to get my leg back in motion and months to walk properly again without a limp. The 2004 graft (taken from my right hip) resulted in a scar only about 1.5 inches (less than 4cms) long that will fade away fairly quickly over the next year, and I was out of the bed the following morning and had no limp after a few days.

I finally returned to work on the 11 October 2004. I must point out here that after 3 weeks I could have returned but delayed due to the nature of my job (I work in the pharmaceutical industry as a Technologist and the risk of

exposure to chemicals is much higher).

I return to the Cleft Clinic in November 2004 for a check-up to establish how the fistula closure has worked (at the time of writing this article everything feels fine and I feel it has being a success). The closure of the fistula is only the beginning of a series of procedures and orthodontics that will take place over the coming few years and that will finally complete a course of treatments that began over 33 years ago. It will be well worth it and my own commitment over the coming months and years is crucial to a successful outcome.

Very important lessons I have learned since March 2004:

The approach today is so different from the 1970's and 1980's. Looking back now, it's maybe the fact that not knowing what treatment was next was the worst aspect, plus the lack of explanation. To be fair this was the common approach then to many procedures.

There is much information out there now on cleft lip and palate, in both web and print form. People need to know how to access these sources. It's important to remember that the indications of treatments available and examples given may not necessarily be suitable for one's own case - everyone will differ. Individual treatment plans will be established from a few visits to the clinic. Time lines of treatments differ as well.

The cost of receiving treatment in Ireland is covered under the public health system. As I happen to have health insurance, this covered my stay in a semi-private hospital bed (as distinct from a 'public' bed).

Treatment for cleft is available under the public health system even for adults. And as an adult with uncompleted treatment it is possible to revisit the issue and receive further treatment.

My speech was naturally affected by the cleft palate, but it's important to point out that my speech, although quite good beforehand, has improved considerably since the procedure.

Hopefully this article will give courage to someone in the course of treatment, seeking or considering returning for treatment for cleft lip and palate.

Sean O'Donoghue
29 October 2004

Family Day, Saturday, 10th June 2006



With 39 families in attendance (approximately 80 children and 70 adults), our second ever

family day was held in the marvellous facilities of the Curragh Military Camp and proved a great success. In beautiful sunshine and high temperatures, a great day was had by children and adults alike, with plenty of activities, including swimming, obstacle course, face painting, bouncing castle, t-shirt painting, soccer, military display, and a wonderful barbeque. The Army proved marvellous hosts, with a number of army personnel helping out in a big way on the day. Many thanks to them!



About the Irish support group:
The Cleft Lip & Palate Association of Ireland (CLAPAI), founded in 1981, is a voluntary support group formed to provide support and information for parents of children affected by cleft lip and palate and those directly affected by the condition.
Website: www.cleft.ie

FINLAND

Finnish research project - a report:

STUDY ON THE SELF-CONCEPT AND SCHOOL ACHIEVEMENT OF CLEFT-AFFECTED CHILDREN IN FINLAND

Ismo-Olav Kjaldman, headmaster of the Kalajärvi comprehensive school in Espoo, Finland, has written a doctoral dissertation entitled "Self-Concept and School Achievement of Pupils with Cleft Lip, Cleft Palate or Both". The dissertation has been written in English and can be found under the following link on the University of Helsinki website: <http://ethesis.helsinki.fi/julkaisut/kay/sovel/vk/kjaldman/>, where it has been published in its entirety after the public defence of the thesis in June 2006.

Kjaldman's study involved research on 175 Finnish school children, who replied to questionnaires when they were 9-12 years old (in 1988) and again five years later at the age of 14-17 years (in 1993). The questionnaires consisted of common questions and a personality inventory test. Kjaldman used quantitative analysis methods to investigate the structure of self-concept and school achievement in the cleft-affected children and such structures were observed in relation to disorder, gender and maturation.

The goal of the research was to survey the self-concept and school achievement of school children with cleft lip, cleft palate or both from their pre-teen years to adolescence. Such research among cleft-affected school children is not common and Kjaldman's study is the first research ever conducted in Finland among this group over a longer period of time.

Self-concept consists of the person's entire personality. Self-concept, as studied by Kjaldman, includes concepts, attitudes and feelings that the person has about himself or his qualities, abilities and relations to the environment. Kjaldman notes that the individual associates experiences to this personality with

earlier observations that he has made in situations of social interaction.

The results of the study show that the basic elements of both self-concept and school success are formed at a very early age and remain constant later on. During puberty, the self-concept simply stabilizes. As for school achievement, even though the structure and form of the achievement changed for the children studied, the actual level of achievement remained stable. Kjaldman therefore notes that early intervention, starting as early as at the age of one, to potential problems such as speech difficulties is crucial for the development of the child's self-concept and later school achievement.

Based on his research results, Kjaldman notes that the existence of a cleft lip, cleft palate or both does not have any statistical significance in relation to self-concept and school achievement.

Very similar results have been obtained in studies of non-cleft-affected children. Kjaldman also found no significant differences between children with different cleft conditions, which contradicts earlier international findings relating to the school achievement levels of cleft-affected children.

However, the results do show that the gender of the cleft-affected child has a significance to the child's self-concept and school achievement. Kjaldman found that the self-concept of cleft-affected boys was stronger than that of cleft-affected girls. The boys had more positive opinions about their self-concept and were more satisfied with their appearance than the girls. On the other hand, the school achievement of cleft-affected girls was significantly higher than that of cleft-affected boys, which according to Kjaldman shows that school success is not necessarily linked with the child's self-concept.

Kjaldman notes that some of the findings may result from the Scandinavian cultural values that do not attach as much interest in what a person looks like than in what he says and does in situations of social interaction. Similarly, the principle of equality at Finnish comprehensive schools, followed in actual practice, may also be

of importance to the results.

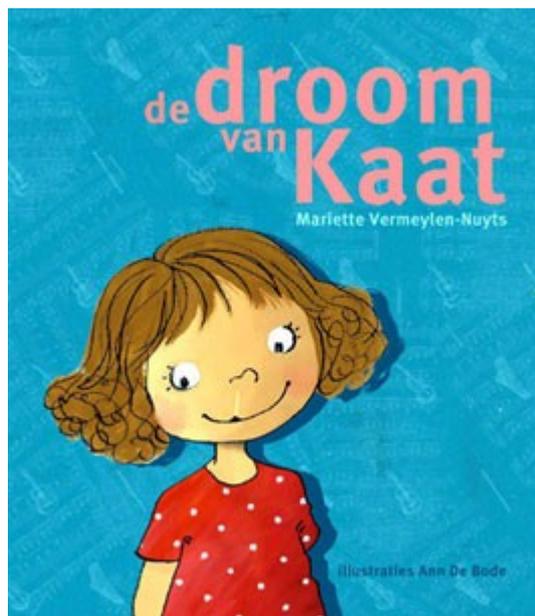
Kukka Antila
SUHUPO ry

About the Finnish support group:
SUHUPO ry is the Finnish national support group. Its main tasks are to give support to new families and those born with CLP, and to champion the rights of cleft patients. Website: <http://www.halkio.fi/>

BELGIUM

The Belgian Association for Congenital Facial Defects VAGA announce the realisation of a new illustrated book for children (5-7 years) born with a cleft.

“De droom van Kaat”, (English translation - “Katie’s Dream”)



The story was inspired by Aline, Katrien's daughter, born with a cleft, and who wanted to learn to play the flute. Illustrations are by Ann De Bode, a well know illustrator in Belgium. 32 pag.- luxe edition – 12,50 Euro
Publication date : October 2006.

From the back cover of the book:

"As the mother of a child born with a facial disfigurement, for years Mariette Vermeylen

desperately searched for an explanation and insight into her family's plight. She studied stacks of medical literature. During her quest, she came to realize that not only parents, but also afflicted children themselves have a need for information and recognition. She could not find one children's book in Belgium that addressed this problem, so she decided to write one herself. 'Katie's Dream' is a story of hope and optimism. A story of acceptance of the things in life that are not possible, and the triumph in discovering what can be achieved. A story for all children with a different face, as well as their families, friends, classmates and teachers."

About the Belgian support group:

Vereniging voor Aangeboren Gelaatsafwijkingen, VAGA vzw (Belgian Association for Congenital Facial Defects) was established in 1992. This self-help group has been granted the Patronage of Her Royal Highness, Princess Mathilde of Belgium, for its outstanding achievements. VAGA is accredited by the Belgian Federal and Flemish Government. The chairperson is Mariette Vermeylen-Nuyts.
Website: www.vaga.be

THE NETHERLANDS

1. The Dutch Cleft Support Group

In the Dutch language this support group is called 'BOSK Werkgroep Schisis'. 'BOSK' refers to the umbrella organization to which this support group belongs. The BOSK is a national pressure group for parents and patients that encompasses several support groups; each one covering a disability or disorder. The 'Werkgroep Schisis' is one such group. The BOSK organization has its own office, where we can have our meetings, a library, and about ten employees who guarantee general backup and continuity. This national head office is located in Utrecht, a nice city in the centre of The Netherlands.

'Werkgroep' means working group: in our case a group of 9 volunteers (parents, patients and professionals) and a co-worker from the BOSK. Their task is to produce and distribute

information, put people involved with a cleft in contact with each other, and protect their interests.

'Schisis' is the official Dutch word for cleft. It is commonly used whether it is about a cleft lip, palate or jaw. Some people use the Dutch word for harelip ('hazenlip'), although we try to banish that habit. Originally 'schisis' is the Greek expression for cleft. The members of the BOSK Werkgroep Schisis meet 6 times in a year. Also each year we set up a parent meeting, alternated every other year with a day for parents & children.

2. Impression of the Dutch Newsletter

The last newsletter from the BOSK Werkgroep Schisis was published in May of this year (2006). The next one will appear around September /October 2006. The newsletter (or in Dutch: 'Nieuwsbrief Schisis') is 6 pages long. It is distributed by e-mail. People may request a paper version. The May 2006 issue contained an interesting article for parents. A summary follows:

[Beginning of article summary]

Beware of new methods without scientific reliability!

This message was concluded by professor Birte Prahl-Andersen, a member of the Dutch support group. She read an article in a free magazine about the use of BPM (bone morphogenetic protein method) to close a cleft lip and jaw. This experiment is not allowed in The Netherlands, because it is not evidence-based. Some surgeons however use BMP as an addition to teeth implementation, but literature about these experiments reports different outcomes. Prahl advises parents: "Don't ever allow your child to be the first one in a new medical method." She remarks also that not all forms of care that are mentioned on the Internet are as yet reliable.

[End of article summary]

3. International conference 2007 in Utrecht, The Netherlands

In 2007 the Dutch BOSK Werkgroep Schisis will celebrate its 25th jubilee. During the

weekend of 5, 6 and 7 October 2007 several activities will take place to mark this special occasion. These events will take place in the centre and surroundings of the nice, old city of Utrecht.

Therefore, the members of the BOSK Werkgroep Schisis and the Jubilee Organizing Committee are happy to invite all known and new participants of the European Network of Cleft Support Groups to the annual ENCSG-Conference which shall be integrated into this jubilee-weekend. Speeches and workshops in this 7th international meeting will focus on the quality of relations between patients and treating specialists. The Dutch organization is able to pay the overnight costs and entrance to the conference for two persons from each participating country. If support groups wish to attend the conference they are asked to send an e-mail in advance to Dick de Haan (aanhaan@kabelfoon.nl). The official registration will take place around Spring 2007.

GREAT BRITAIN & NORTHERN IRELAND

CLAPA Bulgaria trip, April 2006

Report by Gareth Davies, Chief executive, CLAPA

Background

We had been invited to Bulgaria by Iliyana Mavrodieva, a member of the Bulgarian parent's association, ALA, and who has been involved with the European Network for couple of years.

Aims

The aim of the visit was to get a snap-shot of cleft care in Bulgaria, meet with health professionals and parents and get an understanding from them as to what we (CLAPA and other European cleft support groups) might be able to offer in the way of support and assistance. Ideally we would want to support them in their objectives rather than impose ideas from the outside.

Cleft care in Bulgaria

The Bulgarian population is falling and has

dropped from 9 to 8 million in the last 10 years, largely as a result of economic migration. The means that there are currently around 110 new cleft babies born each year, though accurate statistics don't exist.

Healthcare in Bulgaria is funded by the National Insurance Company. Adults must pay into this to receive treatment – if they do not pay into the scheme they will have to pay the hospital direct for any kind of treatment. All children should get free treatment regardless of whether their parents have contributed to the National Insurance Company. In reality, many medical professionals additionally charge their own fees..

All cleft treatment is carried out in Sofia and Plovdiv. There are two surgeons in Sofia, working from different hospitals and the number of operations carried out by each is unknown. One of them charges large sums of money for surgery (we know this from a patient).



The surgeon in Plovdiv, Youri Anastassov, treats around 45 new cases per year. Youri is trained in France (Lille) and over the years has built up a reasonable network of international cleft colleagues and is signed up to Eurocran (multi centre/multi county audit). He is a strong advocate of the team approach to cleft care.

The funding of the unit is precarious. The National Insurance company pays the hospital 250 euros per child for surgery (only surgery). However, this money is spent on high priority areas within the hospital (cleft lip and palate is low priority). All the instruments, computers, printers, anaesthetic equipment, etc., is owned by ALA (the parent's group) and not the hospital. There is no funding at all for speech therapy, orthodontics and ENT – they come in 'as friends'

from other departments.

Feeding advice is given by the nurses but most maternity hospitals do not seem to have any knowledge or contact with the team in Plovdiv and are therefore completely unprepared for the birth of cleft baby (this was evident talking to parents). Where advice is given, there seems to be a preference for the German NUK bottles and teats (known in Bulgaria from 1 year only) The bottles are rigid and the large cleft palate NUK teats are used (placed over the neck of the bottle, they are squeezed to allow the milk to flow)

Surgical protocol is lip closure at 3 months followed by hard and soft plate closure at 10 months. The hospital in Plovdiv is rudimentary though the cleft unit is quite spacious. There was talk of putting a small operating theatre in the unit though how this would link in with more general paediatric and emergency facilities within the hospital wasn't clear. The surgeon is keen to collaborate in inter-centre comparisons (via Eurocran) and is also required to submit outcomes to Smiletrain. He is keen to always improve and develop his techniques.



The visit

A decision was also made early on to take along a specialist nurse (Emma Southby) as we believed (correctly as it turned out) that this was an area where we could offer very practical help and that is often overlooked by visiting cleft teams.

We had been invited to attend a meeting of the Bulgarian National Association of Speech Therapists in Sofia on 28 and 29 April. The second day of the meeting was combined with the Annual Meeting of the parents group, ALA so it was a good opportunity to meet with health

professionals and parents at the same time. We agreed to present 3 papers; 2 from a nursing perspective (Emma) and one from a support group perspective (Gareth)

In Plovdiv we were introduced to the unit and team members, and to parents and members of ALA. We also had an opportunity to meet a couple of patients on the ward. A journalist from a regional newspaper arrived to do a feature on our visit and promote cleft lip and palate.

In the evening we met up with a group of Spanish clinicians who had also been invited to present at the conference; a surgeon and speech therapist from Bilbao and an orthodontist from Madrid. Being able to 'exchange notes' with another visiting delegation was very useful and we also had the opportunity of gleaning an understanding of some of the issues affecting cleft care in Spain.

The following morning we travelled back to Sofia where we remained for the rest of the stay. The Speech Therapists' meeting focused largely on feeding and swallowing mechanisms and we were lucky to have much of it simultaneously translated (either from Bulgarian or Spanish).

Emma and I gave our presentations prior to the parents' meeting. These were very well received (though neither of us had realised that working with a translator effectively doubles the length of the presentation).

A very lengthy discussion took place about people's experiences in Bulgaria (which may not have been dissimilar to the situation in the UK pre-CLAPA and pre-UK cleft reforms, 20 years ago) and how they might move forward. There seemed to be difficulty in defining a set of priorities for ALA - there was so much to do, it was impossible to know where to start. The nurses were very keen to receive further professional guidelines and protocols from other countries and of particular interest was the management of babies with Pierre Robin sequence. The discussion was open ended but it was decided a working group be established within ALA to make key decisions on new projects. That working group will liaise directly with CLAPA.

On a non-clinical note, I have to emphasise how well we were looked after by our hosts during our stay and how welcome we were made to feel.

Future co-operation

How we work together in practice falls into two areas - clinical and professional support on the one hand and support group development and self help on the other.

Clinical support

- Facilitating a visit of nurses to spend some time in London with the South Thames Cleft network
- Facilitating a visit of the speech therapist to spend time with her counterpart in the South Thames cleft unit
- Seeking similar "placements" in other European centres.

Support group support

- Inviting a parent to attend one of CLAPA's Parents Contact Training courses and to allow them to adapt the course material for use in training sessions in Bulgaria
- Invite someone to become a volunteer at one of CLAPA's children's camps
- Help with the cost of translating of information leaflets and books
- Instruction on motivating volunteers and goal-setting using CLAPA's knowledge and experience (a series of workshops in Bulgaria, perhaps)
- Inviting parents/patients to attend meetings and training days of other support groups within the European network

Footnote:

After the visit we received the following message of thanks from the surgeon:

"Dear Gareth,
I was very very happy to have you here. It was very useful and now I see that a lot of people from ALA are excited and are writing in our forum. Some new ideas are coming thanks to you and Emma. I don't have news from the family with Pierre Robin sequence. It seems that Nina is in contact and there is some progress thanks to the nasopharyngeal tube. I hope to keep the contact and will write you from time to time to keep you informed about us.
Thank you again and best."

Polish initiative

A parallel initiative of the European Network of Cleft Support Groups' begins with a planned trip to Poland at the end of September (2006) by Mariette Vermeulen-Nuyts (VAGA vzw, the Belgian Association for Congenital Facial Defects, Emma Southby (cleft nurse in London) and myself. We will be visiting the Centre for Craniofacial Disorders, Institute for Mother and Child, Warsaw. Our host is senior speech and language therapist Ass. Prof. Maria Hortis-Dzierzbicka who has done some groundbreaking projects with residential speech programmes for youngsters with clefts. This trip will help identify how we can be of assistance and support to our Polish colleagues in furthering cleft care in Poland. [Gareth Davies. July 2006]

About the GB&NI support group:

CLAPA was set up in 1979 as a partnership between parents and health professionals. It provides support for new parents, and for people with the condition and their families, from infancy through to adulthood. CLAPA is the only UK-wide voluntary organisation specifically helping those with, and affected by, cleft lip and palate.

Beautiful Bergen, Norway, April 2006

