

HISTORY OF ALA – THE ASSOCIATION OF CHILDREN WITH FACIAL ANOMALIES AND THEIR PARENTS IN BULGARIA



CONDITIONS AND NEEDS FOR A PARENT ORGANISATION IN BULGARIA

The necessity of parent-patient organization that would defend the rights of children with facial anomalies emerged strongly after 1989 – in the beginning of the transition to democracy and market economy. Before that moment such initiatives were not well accepted because it was considered that the state was covering all the needs of its population and there was no need of organizations beyond the official authorities. In order to be justified the state care for the population, a lot of parents were advised to abandon their children in specialized institutions. The main argument for this was that the parents would not be able to take care of “such” child, especially having in mind the feeding difficulties. The feeding tube placed from the first day after birth was not an exception but a rule. The calendar of the surgical interventions and the quality of care were determined only by medical structures without the participation of the concerned parties. Speech therapy and orthodontic treatment were separated from surgery (or in reverse, the surgeons were performing operations without taking into consideration the consequences, connected with the speech or the jaw deformations), a common therapeutical plan was missing. The matter of patient’s and parent’s rights was not discussed because the individual opinion about this and many other issues was not an interest of the state. In contrast to this situation in Bulgaria, in part of the West European countries like the UK,

North France and some Scandinavian countries, the parent's organizations exist from the 70s and in some countries even earlier. This shows that in these countries also existed problems, which were not well solved by the authorities and medical structures, regardless of the high level of medical service. In some Scandinavian countries from the 40s of the past century there is a special law about persons with cleft lip or/and palate. For example in Denmark from the beginning of 40s a National Specialised Centre for Treatment of Cleft Lip or/and Palate exists.

Through the 80s and the 90s of the past century the European Network of Specialists - SCANDCLEFT started its functioning, after that emerged the bigger one EUROCLEFT-EUOCRAN (www.eurocran.org). This network of specialist started a close cooperation with parent's associations in Europe. Under the influence of the parent's associations in west Europe, the calendar of surgeries was changed in direction of performing operations on cleft palate earlier. It became necessary to introduce the multidisciplinary approach, taking into consideration the concentration of cases in specialised centres. In the UK the parent's association CLAPA (www.clapa.com) created an additional group of specialists – nurses, specialised in feeding children with clefts; and one completely original group of participants in the multidisciplinary treatment – Contact Parents. For these achievements CLAPA obtained the status of partner of the Ministry of Health in the area of medical care. CLAPA drew the attention of the official structures of medical care, in order to reduce the number of responsible specialised centres, which after year 2000 were decreased from 56 to 9. This was caused because of the poor results of the centres with small number of patients. Once again these circumstances stand in support of the fact that patients would get best treatment in specialised centres with vast experience and multidisciplinary treatment approach.

Through the 90s in Bulgaria in a context of the problems indicated above, additional negative factors emerged due to the lack of funds in hospitals and the chaos in health care. The idea of creating parent's association was finally realised in 1997, when in Plovdiv was formed a completely new for the country Unit dealing with facial anomalies. Its aim was to create multidisciplinary centre for treatment of facial anomalies. The initiative was brought out by three people: Dr. Anastassov – surgeon, specialized in the treatment of facial anomalies; Zlatka Boteva – speech therapist and Valentina Angelova – parent of a child with cleft and lawyer. The problems in the national health care system were very

serious, however until that moment there was not appropriate hospital structure which could support the association and vice-versa. In 1996 such structure was formed in Plovdiv but due to the difficult financial situation of the country in this period it had serious need of financial support. At that time newborn babies with facial anomalies had to wait sometimes more than 6 months for the surgery because of the fact that their condition was not recognized as urgent and moreover, the planned surgeries were forbidden. In such circumstances some parents were forced to pay charge in the hospital so that their children could have been operated in the period of prohibition of non vital surgeries. The conditions in the orphanages started to downgrade fast, the same situation occurred in the hospitals where money were extorted from parents by various forms and in all specialities. During this period patients were treated in accordance with the regional division. This was another reason for non-compliance with legal regulation which in the case of facial anomalies was established wrongly – the principle of concentration where facial anomalies were treated in specialized centres was approved simultaneously all over the world.

Reimbursement for the surgical treatment was introduced in hospitals for the first time in 2000. However from 2003 on this reimbursement involved surgical treatment of facial anomalies. Presidents of ALA (www.ala-bg.org) at that time - Natalaya Cvetkova and Ekaterina Timcheva wrote several letters to the Ministry of Health Care and the National Health Insurance Fund, asking the inclusion of the facial anomalies in this list of pathologies. It was possible that these letters had some influence because in 2003 facial anomalies together with other pathologies finally were included in the positive list for reimbursement even if the amount was insufficient and distributed in a wrong way.

Even now the problem of the multidisciplinary approach in the treatment stays undecided despite the fact that ALA wrote a lot of letters regarding this subject and lobbied by all possible means to obtain a solution of this problem. For example it is not logical that speech rehabilitation after a cerebral vascular occlusion is reimbursed, while this is not valid in case of cleft palate rehabilitation. The orthodontic treatment for children with facial anomalies is still considered a luxury and does not have any financial support from National Health Insurance Fund. Because of this, Bulgaria stands out with its lack of interest in this socially important problem. The price for surgical treatment of facial anomalies (500-600 leva) fixed by National Health Insurance Fund does not arouse interest or rivalry between surgical teams, traditionally located in Sofia, Plovdiv and Varna.

Indispensable supplies for the treatment of these patients were not bought by the hospitals even though they were receiving some funds by the National Health Insurance Fund. In general speech and language pathology treatment as well as orthodontical treatment were not included in the list of reimbursed pathologies in case of facial anomalies. Such treatment depended on the financial capability of the parents. For 13 years Bulgaria had been fully abdicating from its obligations towards facial anomalies. After 2003 only apparent changes were made. They cannot form reasonable policy of health care in this medical field.

The formation of the hospital structure in Plovdiv through 1997 became possible thanks to the foreseeability and nobility of two doctors: Dr. Nikola Chatalbashev - Head of The Paediatric Surgery Department in Plovdiv and Prof. Philippe Pellerin – Head of The Plastic Surgery Department in Lille, France. At that time Dr. Chatalbashev was vice-rector of Medical University – Plovdiv with long term professional experience in the treatment of facial anomalies. Chatalbashev was a successor of Prof. Sivkov who was the first doctor in Plovdiv that devoted a lot of time and efforts on the facial anomalies treatment.



Fig. 1 Dr. N. Chatalbashev

In Bulgaria in the period between the 70s and 90s, the main contribution to cleft treatment was made by Kavrakirov, Iovchev, Sivkov, Chatalbashev, Klisarov, E. Georgiev and K. Anastassov. After the completion of forming the hospital structure in Plovdiv, this structure started to have main role in the treatment of patients from all over the country. 70% to 80% of all facial anomaly cases are being treated in Plovdiv after the year 2000, thanks to the development of multidisciplinary treatment and craniofacial surgery.

The connection between Plovdiv and Lille started through the 90s, when Dr. Youri Anastassov went on a specialization with Prof. Pellerin. He was also preparing his dissertation on the treatment of children with clefts. Dr Youri Anastassov is son of Prof. Konstantin Anastassov who also has long experience and contribution to the surgical treatment of facial anomalies. Through the 80s he formed in Sofia a centre where apart from surgeons,



Fig. 2 Prof. Pellerin and Dr. Anastassov - Lille, France

orthodontists and speech therapists were also working. However the centre had been existing only for a short time. In 1989 Dr. Anastassov was a resident in the Plastic Surgery Clinic in Sofia, and from 1990 to 1993 passed a residency in Lille, France. In 1993 Dr. Nikola Chatalbashev was on a short visit in Lille where he met Prof. Pellerin and Dr. Anastassov. This was how an idea of forming a new plastic surgery structure of national importance was born. In 1996 the plastic surgery was recognized in Bulgaria as a separate speciality. With the help of the specialists and University Hospital from Lille, the idea of establishing a modern school in plastic surgery in Plovdiv became a reality. This would support the development of the general plastic surgery in Bulgaria, following the example of the French school in plastic and craniofacial surgery which was something completely new in the country at that time.

Through these difficult years of the Transition, ALA Association was created so that the Unit in Plovdiv could keep on functioning. The first instruments of the Unit were either private instruments of Dr. Anastassov or given as a present to the hospital by Prof. Pellerin. In spite of the support from the Management of University and the Hospital in Plovdiv, the Unit was left without a regular anaesthetist and no equipment and instruments were bought. Already in the first year, parents from ALA convinced the German Embassy to donate ALA completely new instruments, granted to be used by the Unit in Plovdiv.

Other donations (financial support) were given by the Gitzi family from Italy, who were living in Bulgaria at that time and had a relative with cleft, treated in the Unit. Soon after this ALA received help from the French and Italian Embassy. With these donations new supplies and instruments were bought. From every visit in Lille, Dr. Anastassov was bringing lots of medicines, surgical flosses and instruments. At that time they were entirely indispensable as the hospital was not giving almost any supplies to the Unit. Until the year 2000 the situation was critical, the worst problem was that there was still a prohibition of planned operations or there were other forms of restrictions, regarding the treatment of children with facial anomalies. The anaesthesia was not defined clearly as only for a very short period of time it was possible to rely on scheduled work of anaesthetists devoted to the Unit. Despite its small resources ALA succeeded to publish one small brochure regarding the facial anomaly treatment and what is more, every year 40 new cases from all over the country were treated in the Plovdiv Unit until the year 2000.

FIRST PERIOD OF ALA

First period of ALA's functioning 1997 – 2000, when the principal task of ALA was to support the hospital structure in Plovdiv and to try to direct the attention of the society to the facial anomalies problem. TV programs with the participation of Eli Zheleva, Lyubomir Karadzhov and Ani Baldzhiyan who contributed to popularization of



Fig. 3 Hospital in Lille, France

ALA's work and the facial anomalies problem were

broadcasted. During this period presidents of ALA were Valentina Angelova, Nataliya Cvetkova and Ekaterina Timcheva. Secretaries of ALA were Mariya i Diana Milusheva. Mariyana Cvetilova was ALA's accountant.

During this period parents, members and sympathizers of ALA were supporting financially in order to purchase non-medical equipment for the Unit. Between 1997 – 2000, the support of the Medical University – Plovdiv was devoted but its financial contribution was very limited. The University and the Hospital in Lille showed great support not only by providing equipment and supplies for the Unit in Plovdiv but also with the intellectual aid of Prof. Pellerin, consulting and operating craniofacial traumas and anomalies every year, when the first craniofacial surgeries started.

SECOND PERIOD 2000-2007 – ALA'S PRESIDENT IS EKATERINA TIMCHEVA

From 2002, the secretary of ALA is Jana Angelova, who has become Manager Development since 2006. Teodora Spasova – speech therapist, was working also as a secretary and organizer of the multidisciplinary team consultations. During these years performed several medical researches on speech therapy documentation taking into consideration the European requirements of Eurocleft. Dr. Anastassov was the Bulgarian representative of Eurocleft - Eurocran network. He presented before the Ministry of Health and the National Health Insurance Fund the European standards for documentation and treatment of patients with clefts. In 2005 ALA and the Plastic and Craniofacial Surgery Unit in Plovdiv took part in Eurocran research program about the gene–environmental factors and etiology in facial anomalies. Dr. Diana Nikolova also contributed to the organisation of the multidisciplinary team by preparing a dissertation about facial anomalies. In 2006 Dr. Anastassov issued a monograph on “Treatment of Facial Anomalies”.

ALA started providing supplies and financial support for 2 speech therapy cabinets – in Sofia and Plovdiv. Since 2000 ALA and Unit in Plovdiv have been taking part in events and speech therapy trainings along the country. May lectures were delivered to dentistry students and resident orthodontists. In 2006 ALA organized a training course about difficulties in feeding children with facial anomalies. The training was realized in Sofia together with Nina Yordanova (www.pumpelina.eu) who became a reliable partner of the Association. During the years Nina Yordanova won recognition as national specialist in feeding children with facial anomalies and especially children with Pierre Robin Sequence.

The contract between Smile Train (www.smiletrain.org) and ALA in 2000 was crucial for the development and survival of ALA. ALA had a contract with Smile Train to

help the Unit in Plovdiv to perform surgeries in primary cases. ALA had a small contribution in return for the development of Smile Train's first online program for registration of facial anomaly cases. Later on Smile Train expands its support for covering also secondary cases and gives additional grants for orthodontic treatment and speech therapy, buying medical equipment, participating in congresses and courses of the Plovdiv team. The contract with Smile Train is still in progress and it is of essential support for ALA and the Plastic and Craniofacial Surgery Unit in Plovdiv.



In 2000 the Medical University – Plovdiv conferred the title of Doctor Honoris Causa to Prof. Philippe Pellerin. The same year the two hospitals signed a contract for cooperation in the field of Plastic surgery, Pediatric surgery and Neurosurgery and an Erasmus – Socrates exchange contract. Prof. Patrick Dhellemmes – pediatric neurosurgeon, and Prof. Remi Besson – pediatric surgeon joined the contracts for cooperation. Since 2003-2004 together with Prof. Pellerin they have visited Bulgaria in order to consult and operate Bulgarian patients free of charge. They also receive their Bulgarian colleagues in France under exchange of experience programs which has become an annual tradition since 2000. On this program over 5 Bulgarian doctors visited France. Several Bulgarian young doctors go to Lille on a specialized training – Dr. Diana

Nikolova and Dr. Regina Hatter – 4 month in the Plastic Surgery Department, and Dr. Stepan Nalbantyan – 1 year in the Neurosurgery Department.

In 2003 ALA received a large donation from Kiwanis – Seclin (www.sites.kiwanis.org) (North of France) – a minibus, medical and office equipment.



Fig. 4 Donation from Kiwanis

During the same period Mireille Godefroy – nurse from Paris, visited Plovdiv and ALA. She made donations and popularized the Association in France. Because of her support she was elected to become an honorable international member of ALA.



A number of foreign physicians have considerable contribution to ALA and the Plastic and Craniofacial Surgery Unit in Plovdiv – Prof. Jose Lopez Cedrun from La Coruna, Prof. Martin Maroto from Madrid, Prof. Gonzalo Gonzalez Landa from Bilbao, Prof. Philip VanDamme, Prof. Aleksey Dobrishev from Moscow and Dr. George Anastassov from New York.



In 2004 volunteers from ALA and the team of the Plastic and Craniofacial Surgery Unit in Plovdiv renovated the Clinic. Orgachim Ruse and other Bulgarian companies donated materials for its realization. Unfortunately in 2005 the Unit is moved to a different not renovated floor of the hospital. A year and a half after the transfer, the former Director of the hospital – Dr. Iliya Batashki, found financial support for renovating the new floor in order to insure its normal functioning. During the period when Dr. Batashki was at the head of the Hospital, it bought medical equipment and anesthesia machine for the Unit.

THIRD PERIOD 2007-2011

The main characteristic of this period is the fact that ALA's national impact becomes grater thanks to the support of Gareth Davis, Anton Vorderman, Emma Southby and Miriam Winkels-Ryan from ECO – a European network of parent associations (www.ecoonline.org). As a result of their visits in Bulgaria in 2007 and 2008, they took the

decisions to help ALA being mediators before official funding structures like TFW (Transforming Faces Worldwide - www.transformingfaces.org), UNICEF (www.unicef.bg), “Tulip” Foundation” (www.tulipfoundation.net) and others. ECO started a pilot project supporting ALA in Bulgaria which aim was to become an example for other European countries.



Fig. 5 Gareth Davis

The initial contact between Gareth Davis – President of CLAPA until 2006, and ALA was established when Iliyana Mavrodieva was delegated by ALA to attend a European meeting of parent organizations. Soon after this first meeting, both Gareth Davis and Anton Vorderman visited Bulgaria. Mr. Vorderman found European partners who donated a big number of computers, monitors and medical equipment. Mr. Davis managed to contact representatives of UNICEF Bulgaria in order to support ALA in its efforts to prevent the abandonment of children with clefts. ALA led an investigation among 70 families and 60 obstetricians, showing that almost 70% of the families of children with clefts still were advising to abandon their children in orphanages.

In 2007 CLAPA financed the trip and training of 3 nurses in the UK who took part in a specialized course for feeding babies with clefts. Those nurses are Sevdjihan Eyubova, Kostadinka Bozhikova and Iren Milenkova – the lead nurse of the University Hospital “St. George” in Plovdiv. ALA together with the Plastic and Craniofacial Surgery Unit in Plovdiv organize periodically similar courses for nurses and obstetricians with the exclusive participation of Emma Southby – Lead Specialist Nurse, Guys and St. Thomas’ Healthcare Trust, London and a



member of ECO.

From 2007 ECO supports ALA in bringing up new priorities – decreasing the number of abandoned children with facial anomalies in the country by improving the knowledge of parents, incompetent medical specialists and the whole society about this matter. This same year ECO and CLAPA provided ALA with information materials for parents. They were translated and adapted for the Bulgarian conditions. A lot of brochures, posters and bulletins were issued and the website of the Association was also improved. From 2008 ALA has started organizing courses for Contact Parents using CLAPA's model that set up a whole network of such volunteers (the initiative was financially supported by TFW). Since 2009 those training courses are supported by the “Tulip” Foundation. The network already has 16 Contact Parents from 7 Bulgarian cities.



In 2010 ECO achieves a substantial progress at European level - a procedure for creating new European standards for the first care of children with clefts was open. It is a big honor for Bulgaria that these new standards will be elaborated under the leadership of the Bulgarian Institute for Standardization (BDS).



Again in 2007 ALA took the decision to create a new position in the Association – Project Manager, hold by Jana Angelova who was ALA’s secretary until that time. In 2010 another position was created – Fundraiser, hold by Savina Maneva. ALA’s aim is to become a bit more financially independent from its international sponsors. In order to improve Savina’s preparation for this position, ECO and CLAPA organized a training course in the UK in 2010.

Representatives of TFW - Jackie Elton, Laura Lewis-Watts and Esteban Lasso visited Bulgaria in 2009 and 2010. In 2010 Esteban Lasso organized Fundraising training, attended by more than 30 ALA members.



2010 is the year when ALA in a partnership with the Plastic and Craniofacial Surgery Unit in Plovdiv won a project, financed by the Ministry of Education, Youth and Science, concerning the creation of a national register of patents with facial anomalies. The project is operated by Dr. Parvan Voynov – resident in the Unit.



The partnership with Smile Train continues when in 2008 they financed the visit of Dr. Nigel Mercer in Plovdiv. He is a specialist in plastic surgery from the UK, being very highly estimated by ECO as a professional. The exchange of experience with doctors from Plovdiv is very useful and some common future plan connected with the creation for the European standards could be expected.

In 2010 Smile Train financed the visit of Dr. Seema Diwan from India. Together with Dr. Diana Nikolova and Dr. Radost Velikova organized an orthodontic training course in order to start the treatment of more than 20 children with clefts.



Fig. 6 Dr. Nigel Mercer

Since 2009 ALA is a member of the National Patient Organization (www.npo.bg), this becomes very important when in 2010 the Plastic and Craniofacial Surgery Unit is threatened to be closed.

In 2010 ALA decided to finance a children room in the Unit. This initiative was implemented together with a renovation of patient rooms, terrace, operating room and ambulatory care room. The financing starts with the campaign of Raiffeisen Bank and Dir.bg with the media support of Nova TV and “Standart” Newspaper, still most of the finances were provided directly by ALA. Due to unfavorable circumstances during the renovation (ALA got an official letter of approval from the Hospital management for this), its successful was in danger. Immediately after the replacement of the Hospital management the legal status of the renovation became questionable. There were rumors about merging the Plastic and Craniofacial Surgery Unit with other structures or moving it to another not renovated floor. After the intervention of the National Patient Organization, the media and other ALA fellow structures, the problem was set. Still ALA was left with a sense of bitterness and the lesson that even when the services for the better treatment of children with facial anomalies in Bulgaria provided by the Association are so evident, certain insecurity always exists.

