## **European Cleft Organisation – 10 years in Bulgaria**

## 1) Background - Why ECO, why Bulgaria?

I first came into contact with Youri Anastassov, surgeon from Plovdiv, Bulgaria at the European Cleft Congress in Manchester, UK, in 1998. He was keen to seek support in developing a multidisciplinary team and parent group in Plovdiv. In the following years whilst CEO of the UK Cleft Lip and Palate Association (CLAPA), I made efforts to reach out to other cleft support groups in Europe and in 2004 organised a conference of European cleft support organisations at the Royal Society of Medicine in London. I was delighted that a representative from the newly formed parent support organisation in Plovdiv, ALA, attended the meeting. This visit compounded our link with ALA and the team in Plovdiv and led to an ongoing dialogue. Subsequently I began to look at ways in which CLAPA could helps under resourced support teams and parent groups in Europe and went on fact finding missions to Poland and Bulgaria in 2007. This culminated in the establishment of ECO in the same year.

### Cleft care in Bulgaria in 2007

The majority of cleft treatment was carried out in Sofia and Plovdiv but some less complex cases were treated in Varna. There were two surgeons in Sofia, working from different hospitals and the number of operations carried out by each is unknown. One of them charged high fees for surgery (we know this from a patient).

The surgeon in Plovdiv, Youri Anastassov, treated around 45 new cases per year. Youri was trained in France (Lille) and over the years built up a network of international cleft colleagues and signed up to Eurocran (a European Union (EU) funded - multi centre/multi country audit). He has always been a strong advocate of the team approach to cleft care.

Resources for orthodontics and speech therapy were severely restricted but some basic care in these areas was provided. The hospital in Plovdiv was rudimentary though the cleft unit was quite spacious.

Feeding advice and support for new families was provided by one nurse. Most maternity hospitals did not seem to have any knowledge or contact with the team in Plovdiv and were completely unprepared for the birth of a baby with a cleft (this was evident talking to parents). It was estimated that 30% of all babies born with clefts in Bulgaria were abandoned by their parents and sent to orphanages on a short or long term basis. I visited three children's homes in the area around Stara Zagora and saw several children and young people with clefts and no other associated problems living alongside some seriously disabled (mentally and/or physically) children. In conversations with some health professionals it became apparent that families were often encouraged to send their children to orphanages because feeding was believed to be an insurmountable problem at home and the child would be too much of a financial and emotional burden on their families There were some children in orphanages who did not receive any cleft treatment at all.

It was recognised during the 2007 visit that the real gap in the management of cleft care in Bulgaria was not the lack of surgical, orthodontic or speech therapy provision (though the latter two were severely under-resourced) but rather the absence of support and referral mechanisms for new families. As a consequence of this, two nurses working with cleft children in Bulgaria (Plovdiv and Varna) were invited to attend a 3 – module specialist cleft nurse training course in Nottingham, UK, between October 2007 and January 2008. This was jointly funded by CLAPA and the European Cleft Organisation. The Head of Nursing at Plovdiv Hospital attended the final part of the training.

## 2) ECO Interventions in Bulgaria 2009 – 2019

ECO has been fortunate to be able to provide invaluable support to cleft care in Bulgaria with financial help from Transforming Faces and Resurgens. The support we offered broadly fell into three distinct phases with different parameters of interventions.

#### A) Phase One 2009 – 2011:

Initial TF support package, developing a project that aimed to reduce the number of babies with clefts being abandoned in Bulgaria. There was to be a three-pronged strategy:

- pilot education training day for front-line health professionals;
- training for parents to enable them to support new parents;
- production of awareness raising material and development of a hot line phone number.

A report on the results of this can be downloaded here:

#### B) Phase Two 2011-12:

A "bridge" period where activities during the initial project were consolidated and priorities and strategic plans set for the next 3 + years. This was the beginning of TFs 'capacity building' approach, pioneered by Esteban at TF.

A report on the 'bridge project' can be downloaded <u>here</u>

#### C) Phase Three - 2012-2018:

Development of multidisciplinary team support with funding available not only for areas supported in Phase One but also direct financial support for multidisciplinary team consultations, orthodontics, speech and language therapy, and, latterly, psychology. Additional grants were provided to help with project management (p/t salary), local fundraising (p/t salary) and for IT support costs, including development of an electronic patient management record system (funded initially by a grant from the Ministry of Education to the Medical University of Plovdiv) and the university of Plovdiv.

Reports on each of the years 2012 – 2018 can be downloaded here: <u>2012 2013 2014 2015</u> <u>2016 2017 2018</u>

## 3) ECO interventions in numbers

Patient no	<u>umbers</u>		
	Seen in MD team*	Speech	Orthodontics**
2012	526	15	30
2013	355	34	30
2014	414	44	30
2015	461	35	30
2016	416	45	30
2017	381	50	30
2018	452	42	30
	3005	265	210

<sup>\*</sup> these are appointments and each child may have been seen more than once
\*\* these are cases funded per year but with roll over from year to year a single

# **Trainings**

	"Front line" trainings*	Nurses trainings	Speech therapy trainings/reviews	Parents contacts trainings/reviews		
2009	1			1		
2010	1			1		
2011	1			1		
2012	1		1	1		
2013		1	1			
2014		1	1	1		
2015		1	1	1		
2016		1	1	1		
2017		1	1	1		
2018		1	1	1		
ATTENDEES	89	55	93	64	<b>30</b> 2	
"Front line"	= healthcare រុ	professionals n	ormally around at the	birth of a child		
2019 Number of current network nurses			15			
2019 Number of current network speech therapists				37		
2019 Number of current network orthodontists				15		
	2019 Number of current parent contacts					

case may feature in two years. See example reporting here

## 4) ECO impact

Perhaps the most compelling evidence that our early work in Bulgaria had made a difference came in the comparison of the results of two surveys carried out firstly in 2009 (at the behest of UNICEF Bulgaria) and then again in 2015.

In a two-month period during April and May 2009, 73 parents of babies born with cleft lip or/and palate gave their answers to questions concerning their child's treatment since they had had their baby. The results were shared with the Health Ministry in Bulgaria. In 2015 to evaluate changes in early cleft care in Bulgaria, ALA conducted the same survey with the same number of families. They interviewed parents of lower age children in order to avoid the same families answering the same questionnaire.

#### Two key findings were extremely relevant to us:

- 1) The number of cleft babies who were able to be successfully breastfed or bottle fed went up from 44% to 64% in the 6 years between the surveys
- 2) The number of parents advised to abandon their baby with a cleft to an orphanage went down from 40% to 28% in the 6 year period

Given that our initial brief was to try to reduce the numbers of babies going to orphanages and that the main reason for this happening was because of inability to feed, these figures showed we were having a positive impact, though there was still more work to be done.

Discussion around the survey comparisons can be downloaded <u>here</u>

For later work in Bulgaria we have definitive numbers for patients being treated and numbers going through the clinic but we have not made attempts to measure patient or parent satisfaction and overall impact. This needs to be undertaken.

## 5) Significant events during the life of the project

#### <u>International</u>

CEN Early Cleft Care Standards 2012 - 16

In developing a European guideline in early cleft care through the European Committee for Standardisation (CEN) we were obliged to find a national standards agency to act as secretariat. We selected the Austrian Standards Institute (ASI) in Austria because of their experience but in a political move we asked them to undertake the work jointly with the Bulgarian Standards Agency (BDS). This meant the final report would be published in Bulgaria, in Bulgarian, and would most likely be picked up by the Bulgarian Health Ministry — which indeed it has been but there have been no Ministerial efforts to enforce it. With Bulgaria having some 'ownership' over the Technical Committee, we were also able to encourage input

from other East European countries who previously may not have been interested in or has the opportunity to join these type of actions.

#### 2013 Research Conference 'Closing the Circle'

We were able to propel Bulgaria onto the European cleft research arena by proposing that it hosted a major international research conference funded by the European Science Foundation (ESF) through the EurocleftNet Programme. This was a key event both for Bulgaria and the ESF as it brought together many East European research participants who hitherto had not had the opportunity to attend international conferences. This put the Medical University of Plovdiv, and the cleft team, on the international map. We were able to attract global experts as speakers in both clinical and research expertise. There were nearly 100 participants with a total of 25 countries represented, 12 from Eastern Europe. There were also delegates from Israel and the US.

The conference received wide publicity in Bulgaria and provided an opportunity for ECO and the cleft team in Plovdiv to meet with the Chairperson of the healthcare committee of the Bulgarian Parliament. The purpose of the meeting was to explain some of the difficulties around cleft care and research in Bulgaria and to try to push for the creation of 'expert centre/s' that would facilitate best practice cleft care, treatment and research.

#### Plovdiv engaging with teams across Europe (conferences, exchanges, EU projects)

Over the past 10 years we have encouraged exchanges of team members with other centres in Europe. Madrid, Oslo and Bristol have all hosted team members funded either directly though Resurgens project funding or via EU funds. There has also been support for team members to attend international conferences (European Cleft Congress 2009 in Salzburg and 2014 in Gothenburg). Since 2014 ALA and team members have also been partners in several EU Erasmus + projects bringing their team into contact with cleft teams in Estonia, Greece, Latvia, Lithuania, Italy, Norway, Romania, Serbia, Slovenia, Turkey and the UK. They are also members of the COST Action 16234 European Cleft and Craniofacial Initiative for Equality in Care <a href="http://ecce.nu/">http://ecce.nu/</a> which has members in 26 countries across Europe.

#### Internal

#### • TF funding core MDT members since 2012

This has allowed a rolling programme of 30 orthodontic cases per year to be fully funded and up to 45 children per year to receive speech therapy, initially for 10 sessions each but since 2017, 20 sessions each. Patients coming into the schemes are selected by ALA based on need and commitment to attend appointments. Total numbers are given in the table on page 3. A huge added benefit to patients is that most can attend treatment near to their home as the orthodontist works across 3 cities (Sofia, Plovdiv, Varna) and the speech therapy is divided up between different

therapists residing in different parts of Bulgaria. The therapists come together for annual reviews and training. All patients are assessed at appropriate intervals at the MDT meetings at the clinic in Plovdiv every Friday morning.

#### • Creation of nurse network 2013

Given that ECO's efforts in the early years were about ending abandonment with the focus on early care (including the CEN guidelines) the creation of the network of nurses was key. This developed from the trainings began back in 2009 and resulted in a structured network of nurses across Bulgaria that could be called upon at any time to assist with a new baby and liaise between families and local health professionals. Paramount has been the ability to ensure feeding is established at home, removing the need for referral to state care. The background to the nurse network can be downloaded <a href="here">here</a> and the current model can be seen <a href="here</a>. The initial trainings were funded by TF and Resurgens but the network itself was funded separately by ECO and ALA. Smile Train is now covering the in-house core costs of this network (but not ECO's supervision). Statistics are recorded and are available on a year-by-year basis for all interventions.

#### Creation of parent network 2012

Training for 'parent contacts', based on model developed by CLAPA in the UK, was originally funded by TF and Resurgens. However the scheme became so popular and in demand that further training was funded by the Tulip Foundation (Bulgaria) and then by a Swiss foundation. The concept is simple – train parents to support new parents in an empathetic and structured way to ensure they adjust well to their new baby, learning from people who have travelled the same journey. It provides extra support where health resources are limited. The parent contacts liaise closely with the network nurses and feature on the ALA website. Statistics are recorded and are available on a year-by-year basis for each parent 'call up'.

#### • <u>Creation of electronic patient database</u>

This has been discussed at length in previous discussions with TF and Resurgens. In summary, its key benefits are

- It helps maintain and manage the remote care models developed by the team in Plovdiv where a lot of treatment occurs far away from the hub in Plovdiv. Practitioners (speech therapists, orthodontists, nurses) are able to enter details of each intervention remotely. Indeed this is also used to manage payment systems to practitioners (no payment until full notes appear on the register). This in turn encourages full population of register for each patient
- Patients/parents can give permission to any health professional of their choice to access their records
- Patients/parents have their own pages where they can share information and photos about themselves with the health professionals treating them.

#### • 'My Story' book 2015

This charming collection of patient stories was developed after ALA ran a competition for 'best story' in 2015. This is potentially a great resource for fundraising. It can be downloaded <a href="https://example.com/here">here</a>.

#### • <u>Media</u>

The media in Bulgaria has been keen to report on activities of ALA, ECO, TF and has helped raise awareness of clefts in general. Its disposition to the issues affecting treatment and families of children with clefts has always been favourable. Media connections developed by Youri and his team should be maintained.

#### Politics and Ministry of Health

Despite countless meetings with government and ministerial personnel, and some 'false promises' along the way, the centre in Plovdiv has still not been officially recognised as a designated centre for cleft care in Bulgaria. Extreme pressure on resources in all health areas mean that cleft care has not been prioritised. This has had a knock-on effect at hospital level: the unit has decreased in physical size rather than increased, despite the fact that the caseload has more than doubled over the last 10 years. Furthermore, lack of official designation as a cleft centre has to date meant that Plovdiv has not been able to join the new European Network for Craniofacial Anomalies – one of the rare disease networks set up and supported by the EU in 2017.

This political failure has left the team frustrated and to some extent despondent for the future. Youri now has his own private clinic and he has argued on several occasions that he would like to transfer all his cleft patients there in order to escape the destructive political landscape. However, ECO has always been of the opinion that we should try to urge state responsibility for cleft care to ensure future generations benefit. This will no doubt be a discussion point in future with regards to where future external funding is allocated.

## 6) Key personnel

There are many who have contributed to the team over the years and newcomers will continue to build on the successes of those who have gone before them. Of the current team members, or those closely connected with the team, the following are core and have worked with ECO since the project began.

Youri Anastassov Surgeon

Jana Anguelova (ALA) Project coordinator

Kostadinka Bojikova Specialist nurse and coordinator of nurse network (trained as

cleft nurse in UK funded by ECO/CLAPA in 2007)

Radost Velikova Orthodontist, developing national orthodontist network

Dani Markova Speech speech therapist, key trainer and mother of a grown

up son with cleft

It is important to maintain dialogue with all these individuals (as well as others suggested by them) and ensure their views are sought in determining future strategies.

## 7) Current Costs

The current project budget for 2019 is appended to this report. Since the TF/Resurgens team funding came on board in 2012, the annual budget has been around 100,000 BGN (around 75, 000 CAD). The formula for calculating costs relating to orthodontic treatment and speech therapy has been case-based, rather than salary-based. The Project Coordinator and Fundraiser are given salary percentages. MDT members participating in the Friday clinics are paid a set fee per clinic. The psychologist is paid to spend 'screening' sessions at the hospital (clinic waiting rooms) and then paid per family for follow up consultations if needed. All other costs relate to training, IT (including National Register development), PR and non-salary fundraising costs and accounting/bookkeeping. This budgeting model has worked reasonably well but of course should be reviewed periodically.

In terms of reporting, we have requested quarterly figures for budget versus actual across all budget lines. They have produced a simple BAV report which is more akin to a record of bank transactions than accounts. They are currently changing this model to comply more with international accounting standards and provide income and expenditure reports for their entire project areas (i.e. not just those funded by ECO) in a consolidated format. This is work in progress and needs to be encouraged and supported.

## 7) Cleft Care in Bulgaria in 2019

Plovdiv now accounts for the vast majority of cleft care in Bulgaria – perhaps over 75 per cent of all cases. There are mostly likely to exist continuing small—time practitioners in Sofia and in some of the other cities but it is difficult to find statistics on these.

What Plovdiv has impressively achieved is a means of really reaching out to all parts of Bulgaria through its professional and parent networks, meaning that the crucial early support at diagnosis and beyond, as well as on-going cleft care (orthodontic and speech therapy) can be provided as near as feasible to the patient's home town. The national electronic patient record system in no small part has been responsible for ensuring the networks function and that interventions taking place at a distance are monitored and recorded.

Moreover, those delivering care within the team have been encouraged to learn and share their experiences with other centres around Europe ensuring practices are challenged and kept up to date and in line with some of the best centres in Europe. The exchanges of personnel, the attendance at international conferences and more recently the participation in Erasmus + projects have ensured that the team has a learning philosophy. Indeed the

orthodontist retains regular contact with colleagues across Europe from neighbouring Serbia as far as Latvia.

Other than the indications provided by the 2015 survey, we do not have concrete statistics on the reduction in numbers of babies with clefts going into orphanages. However, we believe we have created environments that have enabled a reduction to take place. The early care training work and the establishment of the nurse network has been a great success. It cannot be stressed enough that the involvement of parents as an "extension of the cleft team" makes a huge different to the delivery of sustainable and holistic cleft care. ALA in Bulgaria has worked to raise awareness of and 'normalise' clefts in Bulgarian society. This has in turn made it easier to fundraise. The number of parents coming forward to be trained as parent contacts has been impressive and again this type of one to one empathetic support should be encouraged elsewhere.

It comes as no surprise that clinicians from neighbouring countries in Eastern Europe (and maybe even beyond) have commented that they are envious of the national model of cleft care developed by Plovdiv and they strive to achieve the same in their own countries

It is disappointing that the Bulgarian authorities have not been interested in supporting the team's efforts at any meaningful level. The team in Plovdiv is genuinely frustrated that their resolve to become a designated cleft centre has not been fulfilled and, as noted earlier, this has implications not only for their profile in Bulgaria but also beyond in terms of the European rare disease networks (ERN CRANIO). Some kind of pressure, internally or externally needs to be brought to bear on the Bulgarian authorities to find a solution.

In conclusion, I thought it would be appropriate to leave the last words to team members themselves:

# 1) What do you think are the best achievements/advances in your team care and approach over the 10 years?

- The fact that ALA and the Unit in Plovdiv became national thanks to the networks.
- The maintenance of the multidisciplinary team and care very important help and health care it is saving a lot of efforts to the families, granting best possible treatment results with optimal number of interventions. Without it many children would lack appropriate and timely care.
- The existence of the nurse network I believe this is one of the most important achievement related to the decrease of the number of the abandoned CLP children.
- The powerful group of Contact Parents substantial help for the families thanks to their voluntary work.
- The additional efforts of the speech and language therapists have been tremendous very important for the correct long-term treatment of the CLP children.

- Creating of an orthodontic protocol of cleft treatment, according to surgical protocol in Bulgaria. Follow up the results of treatment of minimum 30 cleft patients per year.

# 2) What were the biggest challenges in 2008 and biggest challenges in 2018? Are they the same as in in 2019 or different? What still needs to happen?

- Biggest challenges in 2008 the high number of children directed in orphanages and in 2018 the survival of the Unit
- The biggest challenge in 2008 was the high number of abandoned CLP children as well as the missing multidisciplinary care. The main goal of ALA is to have all the medical care organized and provided by the National Health care system. The Unit in Plovdiv must be recognized as a designated reference Centre. Unfortunately it is not in the government priorities. We are trying hard but no results so far
- A wish that did not happen to be recognized as a Centre of Reference politically we have not be supported.
- Second wish there is no coverage of the other aspects of treatment no advances in the reimbursement except the surgery for the same reason no political support
- -The biggest challenge in 2008 was that there were no experience orthodontist in cleft treatment, and no reimbursement from the country.
- -The main goal of the Association is to refund full orthodontic treatment of UCLP, BCLP patients and support patients with travel expenses to reach the cleft specialist.
- -Also the Unit in Plovdiv to be recognized as a Center of reference.

To invest in keeping the database for more patients and to analyse the long term outcomes from the multidisciplinary cleft treatment.

# 3) What do you think your patients/families would say in answering the questions above?

- I think they would agree in what has been achieved. Most of the families would ask for complete reimbursement of the speech and orthodontic therapy from the state.
- I have a feedback from some parents that they would like to join the Contact Parents network but for the moment we do not have funds from a project partner to support his activity.
- I suppose that parents are following the facts and did not realize that this has been done thanks to ALA, ECO, Resurgens, TF, Smile train and other external help
- Most of the families would ask for complete reimbursement of orthodontic treatment.

# **Budget figures 2017, 2018, 2019**

DRAFT BUDGET 2019 - BGN	2017	2018	2019	
Salaries				
Projects coordination Jana	10,800	10,800	10,800	
Social Insurances	1983	2045	2045	
Finances - Mariana's fee	5,040	5,040	5,040	
Project "Fundraising" - Salary	9,600	9,600	9,600	
Social Insurances	1,099	1,140	1,140	
Salaries		28,522	28,625	28,625
Clinical Support				
Multidisciplinary consultations 30 x 80 leva				
Multidisciplinary consultations-coordination and organazation	2,200	2,400	2,400	
Multidisciplinary consultations-speech therapist	2,200	2,400	2,400	
Multidisciplinary consultations-orthodontist	2,200	2,400	2,400	
Multidisciplinary consultations-ENT specialist	2,200	2,400	2,400	
Social Insurances for the part time contract between ALA and the specialists	1,007	1,140	1,140	
Multidisciplinary Consultations & Insurances	_	9,807	10,740	10,740
Orthodontic treatment				
Orthodontic work - 30 cases per year uploaded in the register	10,000	10,000	10,000	
Expansion materials and brackets - 30 cases per year	10,000	10,000	10,000	
Orthodontic workshop - 10 attendees + 1-2 foreign lecturers			3,000	
Orthodontic treatment		20,000	20,000	23,000

### Psychological support

Screening contacts with families at the Hospital approx. 100 x 24 BGN Following work with 10 families x 4 sessions x 30 BGN	2,200 1,200	2,400 1,200	2,400 1,200	
Social insurances	390	428	428	
Psychological support		3,790	4,028	4,028
Speech therapy				
50 children treated per year x 20 sessions x 25 BGN	25,000	25,000	25,000	
Insurances	2,862	2,967	2,967	
		27,862	27,967	27,967
Speech therapist's (Maria) visit and work with identified trussed members				
Therapists network support and supervision costs-lead therapist Maria Kazakova	1,000	1,000	1,000	
Social insurances for the part time contract between ALA and the lecturer	110	119	119	
Travel cots - 4 visits to different cities approx. 100 BGN	400	400	400	
Subsistence allowance 40 BGN a day x 8 days	320	320	320	
Accommodation for trainer 60 BGN x 4 visits	240	240	240	
		2,070	2,079	2,079
Speech therapists meeting				
Accommodation 10 attendees, 3 experts	1,000			
Coffee and lunch for all attendees- 1 day	700	500	500	
Travel expenses for the trainers x 3	300	240	180	
Lecturer's fees	930	930	930	
Social Insurances for the part time contract between ALA and the lecturers	107	111	111	
Venue costs + Office materials and materials for the training	400	200	200	

Practical instruments for the network work		800	800	
Lectures at two universities - Sofia and Blagoevgard				
Travel costs for two people			200	
Lecurer's fee			620	
Social Insurances for the part time contract between ALA and the lecturers			68	
Speech Therapy	_	3,437	2,781	3,609
Clinical Support	66,966	67,595	71,423	
Data Collection				
Project "National Register"				
Ongoing maintenance costs with quote from company				
domain registration	30	30	30	
domain hosting and e-mail service	84	84	84	
server colocation	1,440	1,440	1,440	
Current software support/development requirements to fulfill original				
aim/functionality of register and costings  Data collection and coordination - Maria Kazakova old and new data 6 hrs per week	2,400	2,400	2,400	
25BGN x 30 weeks	2,000	2,000	2,000	
Insurances - software support/data collection	504	522	522	
Statistics, outcours repport, publication	304	322	1,000	
Data Collection		6,458	6,476	7,476
Data Collection	•	0,430	0,470	7,470
Fundraising, Promotion, Publicity & Lobbying				
Promote work of team and cleft service in Bulgaria				
Medical conferences, midwives and nursing conferences, other organizations*NGO medical sector fees and business trips- 1-2 times a year	1,200	1,200	1,200	
Local network, PC maintainance and web site support				
Technical support (computer networking/maintenance 200 BGN per month from a				
PLovdiv company	2,400	2,400	2,400	
Social Insurances for the part time contract between ALA and a specialist	275	285	285	
Advertising materials - T-shirts, mugs etc.				

Travel to Sofia for relevant meetings with government authorities	1,000					
Fundraising, Promotion, Publicity & Lobbying		4,875		3,885		3,885
Team trainings						
Attending and presenting the Cranio-facial Conference in Utrecht					3,000	
						3,000
Team trainings						
General Administration						
Audit and BAV report	1,000		1,000		1,000	
General Administration		1,000		1,000		1,000
DUDGET TOTAL DUI GARIAN LEVA 1947 1949	DO	407.004	50	407.504		DOI 445 400
BUDGET TOTAL BULGARIAN LEVA - 2017 - 2018	BGI	_ 107,821	BG	L 107,581		BGL 115,409