MY STORY:

stories told by parents of children with facial anomalies

SmileTrain

European Cleft Organisation

BULGARIAN-SWISS COOPERATION PROGRAMME
БЪЛГАРО-ШВЕЙЦАРСКА ПРОГРАМА ЗА СЪТРУДНИЧЕСТВО

The idea of making a My Story competition came after a publication in the ALA Facebook group:

Dear Prof. Anastasov,

We, as parents of a child with the Pierre Robin Sequence, give you our full support. We do not know how to describe our personal story. Indeed, we encountered everything which is supposed to happen when the medical structures are not prepared for such a problem. At the time of the birth, which took place in a private hospital, there was no timely or adequate reaction to the baby's condition although he had been accurately diagnosed. They let the baby suffocate, and then transferred him to a state hospital for resuscitation. The transfer took time, which could have been fatal. We would like to extend our heartfelt gratitude to the team, and to Dr Lazarov in particular, who saved our child, taught me to take care of him and responded to our needs over and over again. On the 15th day we went to a ward which had nothing to do with the syndrome. They admitted us under a "false" diagnosis so that we would not have to go back home but rather be close to doctors and emergency aid, just in case. We also needed special products which you and your department provided for us until we were able to find and buy some. We were discharged from the hospital around a month and a half later. After that, until the operation, we had to be admitted to your department repeatedly in order to try feeding without a nasogastric tube and breathing without an airway. So we came to the ward and were given a room, bed, care during our stay, apparatus, monitoring by specialists: a feeding specialist and an anaesthesiologist, for free. To say nothing of the enormous risk you took with this "illegal" stay. We passed through the post-natal period and all difficulties together with nurse Nelly Hashova. She has always been by our side, supporting us. She was the person we could phone and did phone either at midnight or at 6 in the morning. She is the per-

son who has been to us a nurse, a midwife, a paediatrician, and most all, a friend. She is like a member of our family and there are many reasons why we call her Philip's second mother. Words are really not enough to express my gratitude. You are not just doctors. A doctor is a name for a profession, but when this name goes with a soul, a heart and a smile, it refers to you and the expert team at your ward.

THANK YOU!
PF

Philip, with a nasopharyngeal airway and in a hired car at age 3, has excellent speech and no memories from the adversities in the first months of his life.

This post elicited response from many other people in the group:

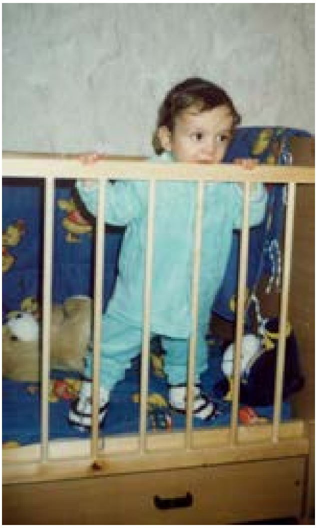
Only a special child's parent can understand this... What it means to worry about his health every day and what it means to have someone help and save him. Our deepest gratitude to the team from our family, too! And Nurse Nelly Hashova is a terrific person.
KK

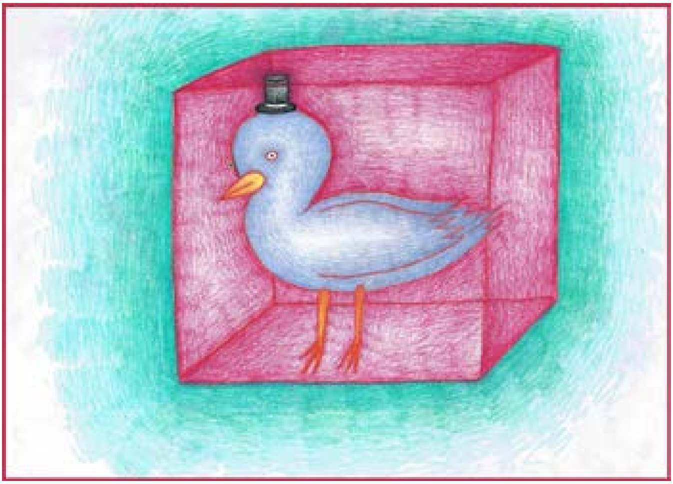
So, the idea of making a competition for the most exciting, most interesting and best written story of a child with a facial anomaly emerged in March 2015. The stories which received the greatest number of likes in ALA's Facebook page would be given awards. We at ALA's Board discussed what the prize should be and decided that it would be best if this first attempt was given a monetary prize, so we announced a prize to the amount of 2,000 BGN. We were immediately concerned that the amount was too big for ALA – we are not a rich association, but we did want it to be motivating and did not change our decision, so at the end of the booklet you will find out what happened. Enjoy your reading and keep some tissues on hand! We thank everybody who shared their stories; I thank Pavleta Pancheva, a former patient of ours, and my son Anton for the drawings. We thank Smile Train for providing valuable support to ALA in the process of treating children with cleft lip and palate ever since 2000. We thank ECO and Resurgence for helping us since 2008 with the creation and maintenance of feeding expert networks, with the projects for additional financing of orthodontic, speech and language therapies, for their assistance in the maintenance and functioning of the multidisciplinary facial anomaly consultation team, and many others. We thank the Bulgarian-Swiss Cooperation Programme for their support in the organisation of the Contact Parent meetings.

Y. Anastasov

THE STORY OF J.P.I. – 389 LIKES AND FIRST PRIZE.

The time has come for me to tell you our tale... a tale which started 11 years ago. Eleven years ago, in spite of everyone and everything, my husband and I made the crucial decision of adopting a child... When we saw Bobby for the first time, he was one year old, I could not even hear what they were telling me: "he's had an operation, more operations are forthcoming"; I was hypnotised by two innocent eyes of a child which did not blink but were fixed on me, as if they were saying: "We are going to fight, aren't we, Mom, and we'll succeed". No further thought was needed; we made the decision that he would be ours on the spot. Very few people supported us at that moment; most of our friends, as well as some people in the family, said we were completely insane when they found out that we were going to adopt a child, a child with a problem at that, a child who would undergo operations... the most important thing was that my husband and I had made the decision; what other people thought – I did not care... if I had given birth to such a child, would I have given him up?... NEVER! I had never come across this problem... While we were waiting for the institutions to officially give him to us, I read materials, articles on cleft palates for nights on end. I wanted to be fully informed, to know. Then, at that moment, I happened to





meet a mother, Katya, whom I am grateful out of all my heart for the courage she gave me at that moment. She had the patience to answer all my questions... My husband did not waste his time either: while I was reading and getting information, he was researching the places where it would be best to take

Bobby to have his second operation for closing the cleft palate (the first operation on his cleft lip had been made in Sofia after he was born). We chose Associate Professor Anastasov and his team. Our little boy was discharged from the children's home on a cold February day and he was officially ours. We named him Bozhidar (God's gift) since he was indeed our gift from God. We came back home... I had three days to get used to being a mother, then we were off to Plovdiv. I remember it was a Sunday, we arrived late in the afternoon but Assoc. Prof. Anastasov was there to meet us and explain what we would do next... I felt relieved; he explained calmly, put us at ease. The lump in my throat disappeared. On Monday the time came when the baby had to be taken to the operating theatre... I had the feeling of countless hours passing before he was taken out of there... When he started waking up from the anaesthesia, I died thousands of times, I did not want to see him suffer. Now I realise that it was at that very moment that I felt what it was like being a mother, feeling anxious about your child, no matter whether you were his birth mother or not, that was my child and I was his mother, and he could only find help and comfort with me and his dad, he had no one else to turn to... We stayed in Plovdiv for a few days, and later I was telling people that there, at the ward, I had seen and found out what humanity was, shown by the entire team, whom I thank with all my heart.

We had been warned that we would probably need a speech therapist so that Bobby could learn to pronounce certain sounds and letters correctly... Believe it or not, I have not taken him to a speech therapist to this day. The speech therapist was me ... a self-taught speech therapist. While Bobby was asleep at night, I would read again – more articles, materials. We would do some exercises and he was just like a little parrot who repeated everything I did without a problem... Today

Bobby is 12 years old, and one can only tell by the nice scar on his lip that he has had a problem. Neither his speech nor anything else could make anyone guess that Bobby used to have any kind of deformity. An ugly duckling has turned into a handsome, wonderful swan. I am very proud of him... Right after our troubles with Bobby had been over, we also adopted a beautiful young lady, and 4 years ago, all of a sudden, their brother appeared: a big, 4 kg baby. Bobby is a sensible and caring big brother to them both... I have never regretted the choice I made 11 years ago, the choice for me to be a mother and for my son to have a mom and dad, to have a family.

THE STORY OF V.V.K.

„Next time I will ask the doctor if he could operate on my ear and implant it into Kaloyan!" These are my husband's words that I will never forget. But let me start from the beginning... Kaloyan is my son; he was born on a very sunny winter day a little over a year ago. It turned out he had a congenital anomaly of his left ear, which was a real shock for me and for everybody around me. To me, he was perfect and for the first couple of days I tried to explain to everybody that his ear was just a little crooked, perhaps a broken cartilage or something of the kind. I spent hours inspecting the small, deformed ear and trying to explain to myself that if they only operated here a little, and there a little, everything would be fine. However, there was a thought I could not get out of my mind: I kept wondering if my baby was the only one born with this anomaly, and if there were other children like that. And I did not even know what was wrong with my

baby because no one would tell me anything. Luckily, none of the hospital staff mentioned anything about leaving him in a home or any other similar institution – I would not think of any such thing, not even for a second. Still, when an otorhinolaryngologist who came to consult us after I had begged him for that a thousand times, declared, having just looked at him from a distance, that "this child is most probably deaf and there is probably something else wrong with him because this is how nature shows us that there is a problem, and maybe it's not only one." While we were still in hospital, I heard about Prof. Y. Anastasov and his team and the maxillofacial ward, so four days after we had been discharged, we saw them for a consultation. Dr K. Gigov and the professor managed to comfort us and answer all our questions, and I am deeply grateful to them for that. The most important thing I learnt was that my son's condition had not been my fault! We found out that Kaloyan was not the only one born with a "small ear", and that there were many other little children like him in Bulgaria and in other countries. It took me a long time but I managed to get to know the parents of other children born with the same syndrome, i.e. Microtia and Atresia! The only thing we had not done until that time was hearing tests since he needed to grow up a little. After we made the tests, we learnt that his hearing was normal and that was the most important thing for me! Right now, Kaloyan is a healthy, joyful and energetic boy – always smiling, he adores music, speaks a lot though nothing is understood, and has many friends. And when a child asks me "what's wrong with his ear", I reply that this is his special little ear and it brings him luck. And yes, I would also undergo an operation to have a small ear like his, or I would give him mine so that he could have two normal ears!

THE STORY OF E.P.H.

Our little prince – our life and happiness. No one can escape from their destiny! There is no flying from fate. There are people whose life runs on wheels, things work for them without any hardships and obstacles; and there are others who need to pass through all sorts of mishaps, to fight in order to succeed. Well, our family belongs to the second type. I am grateful to God that it was us Boyan was sent to! He must have known we were strong, and we would love our little prince endlessly, we would fight together with him and would always be by his side! My pregnancy was completely normal (I do not drink, smoke or take any medication.) All tests were absolutely normal. I had 3D and 4D ultrasound scans. Unfortunately, our little boy was constantly hiding (he would either show his profile or place his hands in front of his face), so we had no picture in which we could see all of him. We wanted our son to have a Bulgarian name with a nice meaning. We chose the name Boyan (ironically or not). In proto-Bulgarian, Boyan means "resilient", "great"; in Persian,

"beautiful", "handsome". I was in my 8th month. I would never forget the day when, while having my regular consultation, the doctor remained speechless for a while, said something to my mother (who was with me) and she was visibly terribly upset... our little jewel was going to be born with a cleft lip! I was shocked! Everyone in my family are doctors, so as soon as we went back home, we opened the medicine textbooks and started reading and trying to find more details about this problem. The truth is that the reason for the occurrence of these facial anomalies remains unknown. Thnaks to my aunt, who is an orthodontist (Dr Nadzhakova), we met Prof. Anastasov. He was exceptionally kind and polite! He showed us brochures of children with various types of clefts, explained the problem in detail, as well as what we might expect, and managed to cheer us up a little. On December 07, at 10:50, our sweet little Boyan was born. I had a caesarian, and the team was prepared that our baby would be born with a cleft. When they showed him to me and put him next to my cheek, I fell in love with him immediately! He was the most wonderful little thing! Regardless of the fact that he had been born with a cleft of the soft and hard palate and a unilateral cleft of the lip on the left. I am grateful to Dr Velev's team at Sheynovo Hospital, and to Chief Midwife Tsveti in particular (unfortunately, I cannot remember her name), who had taken a course taught by Prof. Anastasov and helped me a lot with Boyan's feeding. Luckily, no tubes were needed – baby ate well through special feeding bottles and put on weight normally. There should be more people like her in all hospitals in Bulgaria!!! On 05 February 2010, he had his operation on the lip and nose, then, on October 18, 2010 – the second one, on the hard and soft palate! There is one more operation to come (of the alveolar ridge, round his 8-9th year), orthodontic therapy, speech and language therapy (for perfect speech), as well as a plastic op-

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eration on the nose. But all this in due time, if we are all alive and well. Our little-big man Boyan is a completely healthy and normal boy. He is an extremely energetic, curious, and naughty child who is always smiling! He enjoys the love of his family and his many friends. Here, last but not least, our family wants to express our enormous and eternal gratitude to Prof. Anastasov and his whole team: Dr Gyulev, Mariya Kazakova, and our speech therapist in Russe, Mrs Zlateva! You have no idea how wonderful, needed, important and valuable you are to people like us who, after the happiest event in their lives, have to pass through such emotions and ordeals! May you all be healthy and blessed!!!!! Best wishes and hugs from the Haralampievs, the ballet family (city of Russe)!!!

THE STORY OF I.L.

It was a wonderful autumn day in September nearly three years ago when two bars came up in the pregnancy test. We were all very happy since we had been making plans to have a second child for a long time. The elder brother was the happiest one at the news. After my pregnancy had been confirmed by a doctor, I started along the familiar route. I had my consultations regularly, everything was normal, there was no reason to worry since the baby developed well, until the 21st week of gestation when I made a foetal morphology appointment. On 27 December 2012, three days before New Year, I took my elder son because he also wanted to see the baby and we were off to the medical centre. We could hardly wait to be asked in so that we could see the little boy. While we were waiting, I saw a book of names on the table. I took it and started reading about the meaning of the names I had selected for the baby: Valentin or Victor. After they invited us in, the examination started and the doctor stopped speaking for a while, then she told me the baby had a facial

problem and if he was born, he would have a wolf mouth. The first thing she told me was that I could have an abortion on medical grounds, but if I decided to keep the baby, there was a doctor in Plovdiv, Prof. Anastasov. She could not tell me anything because she did not have any other information, she did not know what happened to these children later. I was stunned: how come the baby had a facial problem, what was "wolf mouth", why did I have to abort my baby? When I told her I did not know what that was and had never seen anyone with that problem, Dr E.P. showed me pictures of "wolf mouth" children on her computer. My eyes were full of tears and although I tried to suppress them for the child's sake, they started running down my face. Alex – this is my eleder son's name – also started crying. I lay back on the couch so that the examination could continue. I stared at the monitor in order to see my little baby's face but I could see nothing. I could only hear that everything elese was fine with the baby, the other words were lost. I could see she was explaining something but I was out of my senses and could not understand a thing. After that, she gave me the pictures from the examination and we left, both in tears. As we were walking towards the car, my son started asking questions: why this was happening to us, why I had to remove the baby, what would happen now, may I not remove him since he loves him very much and can't wait to see him. Questions I had no answers for. I did not know how we managed to get back home; I only knew I was driving and doing everything automatically. My sister phoned at that moment since she had also looked forward to the examination so that she could find out whether they had not got the baby's sex wrong in the previous examinations. But I could not talk to her; I only told her there was a problem and hung up. Thousands of questions swarmed in my head: what had I done wrong, what had I done to make this happen, how come this was happening to me, to us, and many others which were left unanswered. We went home and I pulled myself together a little. I turned on the computer straightaway and googled the name of the doctor Dr E. P. had mentioned. While I was waiting for the information to be uploaded, my mother called and I was again inadequate, my eyes were full of tears again, my voice was quivering, I could not tell her over the phone – how did one tell news like this; crying, I only told her there was a problem and hung up. Soon, she came and after I had explained to her what the problem was, I played the interview with Prof. Anastasov which I had found on the Internet. We saw it together and I managed to get an idea what this anomaly was, though I could not assimilate everything I heard. We looked at pitcures and I came across ALA's page. There, apart from pictures of the anomaly, I could see pictures after surgery. When I saw them, I felt a little better, but the hardest thing was still to come. I had to tell his dad and did not know what his reaction would be. I did not have enough information yet to explain to him what exactly was happening to our little baby. I could only tell him there was a problem, and that the doctor had told me they could terminate the pregnancy on medical grounds, but we could also keep him, and after he was born, he could have an operation. While I was waiting, tears kept filling my eyes. I retired to the kitchen so that my son would not watch me and I would not make him worried, although I knew he was also taking the news badly, thinking he may never see and hug his little brother. I managed to read and gather some more information on cleft lips and palates, as this anomaly was actually called. I was somewhat relieved to learn that there were other cases like mine, that there was a solution, and most important of all, that these children had the chance to develop and grow like any other child. When my husband came home and saw me in

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that condition, he was immediately aware there was a problem. It was very hard for me to tell him what I had learnt but I mustered up some strength and told him the bad news. I related the doctor’s exact words, that is, that we had to decide what to do: have my pregnancy terminated or keep the baby in spite of the anomaly. When he heard they could terminate my pregnancy, he seemed to take this as the solution although I had explained there was another option, too, that our little baby would be operated on after he was born and would then be just like any other child. I could not accept the thought of murdering my child since he was already a well formed, breathing baby. This thought had been torturing me ever since they had started speaking of abortion. On the following day I phoned Dr H, who had been monitoring my pregnancy, and explained what the examination had shown.

I also sent the pitcures I had, together with the doctor's conclusion. She told me I needed to calm down as these were isolated cases and everything would be fine with my next pregnancy. However, I had already read that there was no guarantee this would not happen again, that there were families who had had two children with this anomaly. Then she said they would not do anything before the anomaly was confirmed and we agreed that I would have another foetal morphology scan with a different specialist. Unfortunately, the earliest possible appointment I could make was 8 days later because of the forthcoming New Year and holidays. Those eight days seemed endless. Instead of celebrating and being happy at the larger family we were going to have, we were all desolate at the choice I had to make which was going to change my life forever. My mother, my sister and my grandmother, who came to visit for the holidays, tried to comfort me. They were worried that an abortion could hurt me both mentally and physically since that would in fact be a forced birth, which could cause more serious problems for me. The idea that they were going to take my little baby out dead, or breathing for a second, then expiring in my arms, would not leave me alone. I could not stand this thought and did my best to take it off my mind. What if it turned out everything was normal – how would I live with the thought I had deprived this little thing of the chance of growing, smiling, enjoying life and our love? During those days of waiting I felt his first kick, it was as if he felt something was happening and wanted to show me he was in there, expecting our meeting. I felt him more and more often with every single day and that made me feel even guiltier for having to choose whether to give him life or take it away. I managed to read all available information about cleft lips and palates. On ALA's site, I found there were parents who were willing to share their experience and what they had been through. I read all profiles and put down the contact details of the parent who had a case similar to mine since I had already made my decision though I had not voiced it. The second scan date came, and there I was lying down and watching my baby on the screen. When I entered the room, I deliberately omitted the information that I had had this scan a few days ago and that a facial anomaly had been found. Dr M made the scan but did not establish any anomalies and said that everything was normal, that the baby was fine. I could keep it no longer and told her that some days ago I had been told the baby had a facial anomaly. Then she went on with the examination trying to find out if there was really a problem but the little one was hiding his face with his hands and this was the only thing that made her think there might be a problem. She said that was a baby's reaction when there was something wrong. Besides, even if the baby did have this problem, she did not consider it a reason for abortion, just a cosmetic defect which modern medicine could deal with successfully, that she herself had a relative who had been born like that. Of course, this gave me hope: saying this back home, I would present to my husband a very good reason why I did not have to make an abortion. Meanwhile, Dr H arranged for me a third examination by Assoc. Prof. K. at the Maternity Home ("Maichin Dom") two days after this one. So we looked at baby boy for the third time. Assoc. Prof. K. made a thorough examination, did not give up and had the patience to wait for baby boy to show him his face, and then he confirmed he did have a unilateral cleft lip, though he could not say whether the palate was also affected, but the baby did have a problem. She also confirmed that everything else was fine and there were no other problems. Still, she told me to go and have his heart examined, just in case. I did that later and everything was okay. Also, she advised me to have amniocentesis, though it was late, in order to exclude any other genetic problems. She sensed I had decided to keep baby boy. Having that in mind, when we went out into the corridor, she told me, on the basis of her experience, that there was a considerable possibility of making an unnecessary abortion. This made my internal decision of giving life to my little treasure even stronger. Apart from my own experiences, I would like to share something that happened while I was being examined by Assoc. Prof. K. I had to get up so that another doctor could use the apparatus. The doctor in question almost laughed that so much time was being spent on me for a simple cleft. At the same time, a patient of his showed up at the door looking desperate, and he shouted at her for asking if there was no way she could keep her baby. Without thinking, he snapped: "how would you keep that calf, do you know how many convolutions a calf's brain has?" Obviously, the baby had a serious problem but that is no way to say this to a woman who wants to keep the most precious thing in our lives – our kids. I was secretly happy I had not come across a doctor like that one. She was in my situation, I knew how she felt, but unlike her, I could save my baby. All those days I would reread the information in the forum I had found over and over again. Reading, I only took in the positive aspect, that everything could be remedied. I even thought the side effects, such as problems with the teeth, speech and ears, were insignificant because nobody had any guarantee how teeth would grow, whether a child would speak or hear properly. The parents of any other child born without a cleft lip or palate could also face all these problems. While I was pointing out the reasons why I was supposed to have our child, my husband was pessimistic and only saw and accepted the negative side. That was why I made an appointment to see Prof. Anastasov and his team. After I had fixed the time, I asked my husband to accompany me to Plovdiv so that we could talk to the professor; I hoped his decision would change after the meeting. The fact he agreed made me feel a bit better since there was a hope he might see light at the end of the tunnel. And so we left for Plovdiv. When we arrived and were asked in, I was amazed at the attitude Prof. Anastasov and his team showed us. They patiently listened to the questions my husband asked (I had no questions since I had read everything possible), they replied and explained everything in detail, they did not try to impose their opinion on other people and talked about things as they were. We had the chance to see a child after lip and palate operations. When we saw him, we could hardly believe he had been born with a bilateral cleft of the lip and palate. He was an incredibly cute little thing. My husband seemed afraid to enter and when he finally ventured in, the only thing he said was: "All babies are cute when they are small. What shall we do with him when he grows up?" I realised his decision had not changed. My fears were mainly related to the possibility of someone hurting my older son by saying something wrong about his little brother, whereas my husband accepted the threat of having baby boy born with all kinds of side effects and we being unable to cope with them. That was the difference in our thinking: I knew we were going to cope with all this, and he did not believe in that. After we left the room, we met another family in the corridor. Thir child was being discharged after a palate operation. I spoke to the mother and after I had once again confirmed my decision, she told us everything was in my hands. I went back home and I asked my husband about his final decision after all he had heard and seen. Like a drowning man would clutch at a straw, he said: "Everything is in your hands." Then I replied I would tell him my decision after I had had the amniocentesis and had learnt the results. Though I felt and knew there would be nothing else, that this was an isolated case, it would be very different when he had seen it written in ink. The following week I was admitted to hospital for amniocentesis. I had to stay there for 5 days during which Assoc. Prof. K. and I watched baby boy on the foetal morphology apparatus in order to see if he might also have a cleft palate apart from the cleft lip. There was no 100 per cent confirmation. Thus days passed and the results were ready. It had already been documented that there were no other morbidities, there was no reason for worry, no genetic modifications: everything was within the norm. During my stay, they ran for me a presentation of feeding bottles and teats. After the presentation, I spoke to the girl and explained that our baby was going to be born with a cleft lip and palate and asked her if they happened to offer products for babies with special needs. Then she replied they did not but she could give me the phone number of the woman who imported such products, so I could talk to her. I thanked and wrote the phone number down. After I had been discharged with the test results ready, I went back home and announced the decision I had made long before that. My little baby was going to feel his mother's embrace, he would give us his smiles, together we would study the world around us, he would take the place that belonged to him in this world, together we would overcome all difficulties. After almost a month of days and nights filled with worry and tears, I was finally at ease, and so was everyone in my family. I went to my consultations regularly, baby boy was growing and developing by the book. I contacted the parent whose telephone numbers I had written down. Apart from the telephone calls, we were also able to meet and talk about everything that was of interest to me. He showed me pictures of their little sweetheart and I showed them to my son so that he would know and see that his little brother was going to be just like any other child, that everything could be fixed. I managed to find out which hospitals had nurses trained in first aid for such children and was very happy to learn that there were such nurses in the hospital which I had chosen as the place to have my baby. I also wrote the telephone number and a little later contacted the nurse. We spoke and she said that she was still working there, so if I had any questions, I should feel free and talk to her, and we could also meet before the birth, if neces-

sary. It happened so that a month before the birth I had to go to hospital. However unpleasant all that was for me, I still had the chance of surveying the place since this time I had decided not to choose a particular team for the birth. I got to know the medical staff and informed them that baby boy had an anomaly. There was one female doctor who harshly reacted to the fact that I had decided to have this baby but after that she did not say a word. I met and talked to the nurse who had been trained to provide first aid to children born with cleft lips and palates. I told her I was worried about feeding baby boy after the brth since I had read that in many of the cases these babies were fed with a tube without any attempts at feeding them normally. She replied that they would put a tube only after they have been convinced that the baby could not be fed with a teat, which was comforting. I also asked her if I had to bring some of the special teats and if a feeding specialist would be let in if necessary since it turned out she was not in the neonatology ward. She answered that such teats were not always needed so I shouldn't hurry but rather wait for the baby to be born, and that there would be no problem for an external specialist. I was very glad to hear all that and was pleased with my choice of a hospital. During my stay I met a mother. When we got to know each other and she found out about baby boy's problem, she told me she had a child who got an almost incurable impairment as a result of a doctor's mistake and though everybody tried to convince her that she should leave him in an institution, she took him and fought for his survival though he would never be able to live without her help. That made me think that in many cases, whatever the problem might be or however insignificant, in the point of view of the birth team the only option was to terminate the pregnancy or make the parents give their little ones up. That gave me more strength and confidence that I would be able to cope with everything which lay ahead. On the basis of everything I had read, I knew that the first year after the baby's birth, and probably after that as well, would be tough. Time passed, and days slipped away. I contacted the feeding teat importer and explained what was expecting me. Then she told me that I should not hurry with the purchase of something which may not be useful for me, and that they would provide teats and bottles for me at the hospital if that was indeed necessary. Since my birth was planned as caesarian on medical grounds, I just counted the hours till the time came for me to go to hospital, till the moment when I would see my little treasure, hear his cry and find out whether he was safe and sound, whether the cleft was a full one or if it was just the lip. On May 13, 2013 I was admitted to the ward early in the morning and several hours after that my little hero was born: Valentin. The Valentin – Viktor dilemma had been solved the moment I found the baby would be born with a problem. Valentin was the name that would determine a better fate for him: to be strong and healthy, to make friends easily, to adapt in every situation, etc. After he had cried out, my tears ran down with excitement and then the anaesthesiologist asked me why I was crying if I had made the decision to keep him. I answered the reason for crying was the joy and excitement I had also felt with my first birth. They showed him to me and the first thing I asked them was if the palate was affected, too. They replied that as far as they could see it was just the lip and they would be able to tell for certain after he had been seen by the maxillofacial surgeon. Then they gave me the phone to call his dad and told me he would be able to see him for a couple of minutes after the baby had been bathed and measured. I was happy and calm. When they finished the operation, they transferred me to the recovery unit. I called my husband and he said that he had seen baby boy who was very cute, and he had taken pictures of him and would send them to me since I had not been able to see him well because of all the excitement, and the tears, and because he was crying. In the evening they surprised me by bringing baby boy in so that I could see him. I had not expected that since I knew that after the caesarian we would not meet until 24 hours later. The nurse even placed him in my arms and I could finally hold him and kiss him. She said he had not been seen by a surgeon yet but they would inform me as soon as that happened. She only left him with me for 5 minutes but they were enough for me to realise what mistake I would have made if I had let them take away his life. On the following day they helped me get out of bed and transferred me to an ordinary room. After they had made sure I could move on my own, they fetched baby boy. They gave me the good news he had sucked at the teat and could be fed without a tube or a special teat. That meant he would be with me all the time, and no special monitoring would be necessary. They also told me the surgeon's opinion was that he only had a cleft lip so I felt relieved since I had been prepared for the worst possible problem: a full unilateral cleft. This was the lesser evil. After he was back in my arms, I knew we were going to overcome any difficulty. I watched him with admiration but still I noticed there was something wrong with the gum: it was not properly shaped. So I phoned the Plovdiv team and asked them to accept us and examine him right after we were discharged from the hospital. I was lucky the day was Friday, which coincided with Prof. Anastasov's consultation day. I asked the personnel to discharge us first, if possible, and prepare all necessary documents as quickly as possible because we would have to travel to Plovdiv straight after leaving the hospital, and they were sympathetic. On the day of our discharge, everything was ready and we set off for Plovdiv in the quickest way possible. Though we travelled fast, we could not meet Prof. Anastasov but the other specialists from his team were waiting for us. When we arrived and went in, they examined baby boy and found out the cleft had affected the gum too. So the final diagnosis was unilateral right cleft of the lip and gum. We discussed the operation to be made and were given a list of the documents and tests I had to present when the time came for the operation. We agreed that I should phone a month before the end of the baby's third month and make an appointment for the operation. We set off on our return journey to Sofia and when we came home, there was a little family party organised for us. We were all very happy and pleased that things were going in the best way possible. The days passed, our little hero grew, ate well and put on weight although there were times when the feeding lasted for over an hour. But this hour was the best thing since we felt each other, got to know each other and my thoughts and feelings were just for him. This may sound selfish but his dad and older brother also devoted their free time to baby boy. His brother was my main assistant and would not let the little one feel any kind of distress. The moment he started crying, his big brother would pick him up and hug him. And he cried very often since he took in more air together with the food because of the cleft and that caused severe colics. My fears about my older son's reaction when he saw his little brother proved unnecessary: he loved him the minute he saw him. He would invite his friends home and they would give no indication whatsoever that they had seen the problem. One day a boy just asked me why his lip looked like that and I explained. Nevertheless, everyone liked him a lot, especially his large blue eyes, and said he was very cute, they played with him and did not ignore him. We went out for walks without feeling uncomfortable and got used to the cleft to the extent that we could not imagine him looking differently.

The time for his change came. We left for Plovdiv a day before the operation. My aunt insisted on accompanying us though I had told her not to come because there would be no place for her to spend the night at. Still, I felt relieved that I would not have to wait all alone until everything was over, that there would be someone close to support me. In the late afternoon they admitted us to the ward. Although I knew everything would be fine, I felt anxious. It took me a lot of time to go to sleep, with my little treasure in my arms. In the morning before the operation, Prof. Anastasov came to see us. He explained what the plans were, and that our operation would be the second one, and that everything lasted around an hour and a half or two hours. It was the last time I had been looking at the baby's little face in that condition. I wondered what he would look like after the surgery, whether the change would be a major one, whether he would be able to eat straight away since he had not eaten for over 8 hours, and he was not one of those babies who waited patiently for their milk: he started crying the minute when he had to be fed. To my surprise, he did not seem to be hungry at all. He was lying peacefully, playing with his hands. I was reading him his favourite story of Peter Pan. Tinker Bell's name sounded very funny to him.

And so the operation hour came, he was taken to the operating room and the waiting began. Time passed slowly. In order to take my mind off what was going in there, I offered my aunt to go downstairs to the caf and wait there. I kept looking at my watch, and after an hour and a half we went up to the room again. Soon afterwards the operation was over and my little boy was brought in. They placed him on the bed and when I saw him I could hardly believe that was my baby. He looked incredible. Unfortunately, our joy did not last long; all of a sudden blood started coming out of his little lip. It became more and more and he started choking. I was frightened, called the nurse, and when she came together with the young doctor, they examined him and saw that some of the stitches had been loosened. They started to aspirate the blood so that he would not swallow it. They said they had to stitch the lip again and took him back. However, we had to wait for the other operation to finish. I stayed in the room, trembling, tears all over my face, wondering if everything would be fine this time. They told me they would return him in an hour and we decided to go out and get some fresh air. There was nothing we could do but wait. Though I knew my treasure was in the best hands possible, the feeling of anxiety would not leave me. I was grateful my aunt had not changed her mind about coming with me because we were not alone; she tried to console me and helped me at those difficult moments. When we went back to the ward, they were taking the baby out of the operating room. They put him on the bed. He looked peaceful, maybe because of the anaethesia. He was still under its influence and looked completely powerless. The only thing I cared about at that moment was that he would wake up so that I could see the sparkle in his big eyes. Soon he came out of the anaesthesia and to my surprise, the little thing gave me his most wonderful smile. I had no idea where he had got the strength for that but he made me extremely happy. At that moment he was my hero and gave no sign that he was in pain. He was incredibly calm. I prepared his milk and he drank it within seconds, a few seconds only. His sucking reflex had been restored, he sucked without any effort. Once again he gave me his beautiful smile and soon fell asleep. Now everything was okay, everything had ended successfully, and I was happily looking at a baby who was perfectly healthy. I could not take my eyes off him, he was so different. Within a couple of hours he had been transformed. I was so much used to the way he looked and accepted that image that it felt like I was not looking at my own child. Later Prof. Anastasov visited us to see how the little one was coping. He explained in detail what they had done; he told me that apart from the operation on the lip, they had also restored the gum as much as possible and placed the two halves against each other so that they would join while he was growing, and if necessary, the next surgery would take place when the boy was three. There were no more unpleasant surprises and we were discharged, safe and sound. They explained what I supposed to do at home and scheduled a consultation a month later. At home, everyone was looking forward to our return. They welcomed us and when they saw us in reality, they were astounded by his change. It was a bit harder for his big brother to accept this; in the beginning he would even say the baby used to be cuter, but everything in its time. It is in man's nature to adapt and survive in any situation. A month later we had our consultation. Everything was going well. Once again we were given instructions as to how we were supposed to take care of the surgical site and clean it. We agreed they were to see him again after he was one year old, and went back home. Time passed imperceptibly and the baby grew very fast. First he could sit, then he could stand and move on his own, he started saying his first words. He started with mom, dad, granny, brother and before he was a year old, he already pronounced every word he heard correctly and even learnt to count to ten. Before he was a year old, he started walking, and a little after that he started making simple sentences. His speech was clear and comprehensible. Our little treasure changed with every single day, and so did the surgical site. His nostril was either equal to other one, or slightly lower. On the one side his lip was a little raised but that did not worry us because anything could be corrected. He had all his teeth. The upper ones are a little crooked but with the help of braces he would have the most beautiful smile in the world. There is a tooth in the fissure in the gum which did not grow, perhaps due to lack of bone tissue to build it. After he was one year old, we visited Prof. Anastasov's team for another consultation. They said a slight correction would have to be made but that would be at the time when they operated on the gum.

And so our little hero is growing and making us happy. He is already two: a smart, lively and curious child who notices everything. Now he is about to start going to a nursery school and my worries are no different from any other mother's: how he will take it being separated from me, how fast he will get used to the new place, and similar things. I recently read a letter from a child to her mother. Quoting it, I would like to express my deepest gratitude to everyone who stood by our side in our pain and suffering and helped us go through and overcome this ordeal. I would like to tell everyone who is about to walk the same path: you are not alone; there are people you can rely on and trust, do not keep to yourselves and suffer but take this as another test in life which will make you stronger and raise your spirit.

"My dear Mom,

I know it is not easy for you ... but I want to tell you something that you may not know yet. Before anyone gets a body, each soul already knows which road it has to walk, so I also knew I would be born in order to get certain experience. Did you know that? There are more or less elevated souls so do not always trust what seems to you the most logical thing... this is not exactly the case. The choice to be born and live an unusual life – let's call it "difficult" – is a hard and painful one. But it is the choice of love and only souls which are very sensitive and elevated can afford to make it.

You have no explanation for that? You are right, it is not easy to understand, nothing is so simple. But trust me, physical appearance is not what matters... and you know that my soul is pure and wonderful – this is what really matters and you realised it as soon as you took me in your arms for the first time.

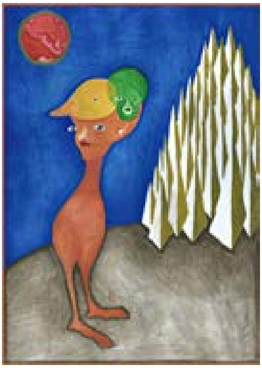
In fact, each one of us chooses their own parents: I looked *for you and found you, this is so nice! I had to be sure that I would be accepted and loved unreservedly; I had to find two such souls, beautiful ones, like you and dad. I hope you will be pleased to learn that you are accomplishing a superior mission which can only be assigned to few, which has been assigned to you by Heaven. You know, some mothers – you are not among them, I know that – have a hard time going through this experience, through this knowledge. They almost accept it as a punishment and do not realise that for a human being who has great capabilities and love, the acquisition of such delicate and sometimes painful experience is an award. It can give you a multitude of unique, indescribable moments... you and me know them, don't we, Mom? They cannot be told in words but can only be felt through the emotions... or through the ethereal energies we exchange. Mom, how much I would like you to tell this to all the people who ignore the dance in our different types of existence... Well, it does not matter for the time being, it is enough I have shared with you something that you have known deep inside yourself... I just wanted to confirm your intuition. We are all creatures of light who come down to earth from time to time in order to learn the next page of their lessons. Our two lights are so much alike that they recognised each other: you were born to wait for me and I came here in the way described in the book of fate (with a pen full of golden ink). I embrace you, Mom, and thank you for being what you are and for giving me all your love. You needn't worry, you already understand everything; you should trust me at least as much as I trust you and then we will continue our dance to our music which angels have written specially for us. I love you, you love me ... love is the answer to everything!*

Signed by: Your Source Child:

Excerpt from the book 'Healthy and Happy Children through Dr Bach's Therapy with Plant Blossoms'".

THE STORY OF I.V.

Dear friends, I am not very good at writing but I have decided to share our story. In the hot night of the 19th of August 2013, our little 'ugly' duckling HRISTIYANA was born. Marked by fate in an unusual way (born with a cleft lip and palate) but a real little treasure. After her birth in the state hospital in Vratsa, my husband and I were truly shocked by the old views and the rude attitude of doctors and staff, complete lack of interest and no information about our little treasure. They would not let me hug her after the birth, the neonatologist had fed her with a tube and after thousands of pleas and tears from me, on the second day they let me go to her. During the time we spent expecting our short meetings with baby girl, her father and I looked for information on the Internet about what we were supposed to do next. Thus we learnt about Prof. Anastasov and his team in Plovdiv. On the 4th day the doctors told me I was going to be discharged, and our baby girl's care pathway was also over and I had to take her home and feed her with a tube or leave her at an institution. I was shocked and terrified at the thought of leaving



my little baby with strangers who did not care about her, but I had no choice – I could not cope with the tube feeding. So we left her at a children's home in Vratsa. We looked for Prof. Anastasov and arranged to see him. In September we travelled to Plovdiv accompanied by a medical expert from the home who was responsible for the feeding. When we arrived at the hospital, we were surprised and amazed at the attitude and attention the professor gave us and the thorough information we received about what was ahead of us. Nelly Hashova fed the little one with a special bottle and there was a miracle! My little heroine started sucking greedily as if that was the thing she had been doing since day one. They gave us the bottle so that I could start feeding the baby girl, first at the home, under supervision, and later – at our own home. At the end of September, after a lot of effort and problems with the social workers, we managed to bring the baby back home and a month later we went to hospital for the firt lip operation. Everything went fine, including the recovery. When she was ten months old, we had the second operation, of the palate and the gum, and a little later shunts had to be placed in Hrisi's ears after she had otitis in both ears. Today, 2 years after the awful August 20th 2013, everything is fine, my princess is growing and getting more and more beautiful, her father and I and all her older brothers and sisters (we have a total of 7 children) know that we need to meet some more doctors, speech therapists, orthodontists, but we also know we would never give up our little ‘ugly’ duckling who is already turning into a beautiful swan. Our heartfelt gratitude to Professor Anastasov and his whole team for the happy end of our fairy tale! We thank you and respect you deeply! And to all of you who have our fate, I would only tell you: ‘Be strong, everything can be remedied – children are a gift of God!’

THE STORY OF TS.D.

Our story began on a cold winter day. The date was 19 November 2011. A day we will never forget. That was the day when my first child, my sunshine we named Alexandra was born. A name we subconsciously chose, having no idea what we would have to pass through. A name I connected with power and thirst for life. But of course life sometimes plays with us. It did not bypass us. Our happiness was clouded. On the one hand, the uncertainty of what it was like being a parent, and on the other hand, right out of the anaesthesia, with the mind still blurred with pain and happiness… While I was still under the effect of the anaesthesia, my family had already seen her. A beautiful little baby who was physically healthy but marked by nature in an unusual way. While they were fluttering about outside, wondering how to deliver the news, the paediatrician advised them to be careful what exactly they were going to tell me. I will never forget my husband coming in, and the joy I read in his eyes together with something else, an anxiety I could not figure out. Then there was my mother. I do not remember what exactly we talked about apart from the moment when he told me about the lip and … I had never before encountered such a problem. I was left alone, and I could not get up on my own yet, so I asked one of the doctors to bring her to me so that I would meet my

princess. They brought her in a trolley. I shook all over – I had not expected to see that. I did not cry, just froze for a minute and did not know what I was looking at... Was that my child? It could not be happening to us; how did we deserve it, where did we go wrong...? I was afraid but still I touched her little hand through the bed bars, I felt her. That was my ugly duckling. The child with whom we were going to pass through hell. They discharged us and we started looking for telephones, doctors and so on... We made an appointment to see Prof. Anastasov at St George Active Treatment University Hospital in Plovdiv. She was 3 months old when she had the operation. On February 14, 2012 I was in the ward, trembling. I had left my most precious thing in the hands of strangers. They placed her under anaesthesia and took her away. My husband had not come yet, and I walked up and down the corridor. It seemed the waiting took days. Just silence after her cry that I could still hear in my head. At one point, I saw two doctors running somewhere but they had no time to tell me what was going on. It turned out they had had to find a surgeon to perform venesection (I am sorry, I am not sure how to write this – I have no medical qualification). Tears and silence and there she came, back to mom and dad... My strong girl had made it. The sight was not a pleasant one: a baby's fragile body coming out of the anaesthesia, making funny sounds, her body wriggling with pain. Then the residents came, and the nurse started explaining the case to them. My husband and I stood beside them, and I felt angry at being unable to see her. There were thousands of questions in my head: would she be able to eat... When the residents left, we spoke to the nurse. She advised me to try breastfeeding her after she woke up from the anaesthesia. We did try and managed, in spite of the pain... Three or four days passed in the ward. On the last day they removed her sutures and saw us off having given us instructions as to cleaning the wound and asking us to go to consultations regularly so that her condition would be monitored. I would like to thank Prof. Anastasov and his whole team, as well as the ALA organisation for everything they did for my child and for us. They were by our side both physically and morally all the time. To me, these people are angels. They are among those special people who cannot be forgotten and leave a permanent mark on our minds. They are so pure and dedicated, unmarred by material demands... Prof. Anastasov's words still echo in my head: "keep them, the child now needs them more..." I bow

my head in gratitude to them! Now my princess is 3 years and 6 months old, and 4 months ago she became the proud older sister of a little boy. I admit we were afraid to have a second child. We spent nine months of anticipation and uncertainty whether this whole thing would not be repeated again... The moment I had my baby, I felt relieved: we had a boy! Now I am happy and enjoy every single day with the children. Yes, we constantly need to answer questions about what the matter is with her lip but still I know how to reply to each one of them. When I think she is ready, I will tell her the whole story because she deserves to know... This is one part of our lives which was filled with a lot of pain, fear and gratitude. But it is already in the past and we have turned our backs to it, and we are prepared for the new challenges life will present! Someone once told me that fate only brings to their knees strong people because it is aware that they will find the strength to stand up and move on!

And so our story began on 29 April 2012, the story of a wonderful boy with harsh fate, ironically doomed to struggle from his very first breath... Nicky was a most desired and long expected baby, and in spite of the monthly consultations and examinations by various obstretricians, no one noticed there was something wrong with him. Everyone assured us till the end that he would be born a big and healthy baby but reality proved different. The birth itself was a very hard one, he was nearly suffocated, and then, at 21:00 sharp he came into the world! The only thing I remember from that moment was the doctor's shocked face and the subsequent diagnosis. The little boy was born with a full cleft of the lip, palate and gum and accompanying blood infection. My whole world collapsed within seconds: I had no idea what that diagnosis meant, what would happen to my child, how my family would take it. For a moment, thousands of thoughts passed through my mind, together with the inevitable one: why my child?! They showed him to me for a second and took him out, and the baby did not even cry when he was born... They had to put me under a general anaesthetic to have my stitches done, and while I was coming out of it, I remember talking in my sleep, asking about the baby: whether he was okay, would he be all right, and the uncertainty and panic that had seized me due to the complete lack of information almost killed me. I will never forget waking up from the anaesthetic in the hospital room and seeing, right above my bed, the night lamp shadow forming the shape of an angel looking upwards (that is the picture attached with our story). On the next day they brought me Nicky – to see him and hug him for the first time. This was the most beautiful and innocent boy, with ink blue eyes fixed on me questioningly. Due to the complications in his condition and his blood infection, he had to be transported to the neonatology ward in Pazardzhik. There I spent the longest and hardest 3 days in my life: away from my baby, I had to hold on for his sake and for the sake of all the people whom I loved and who loved me! Luckily, in Pazardzhik we met a wonderful team of experts who taught us how to feed him and look after him, and then directed us to Assoc. Prof. Anastasov. We called and made an appointment, and soon we were in the ward where we had the honour of meeting the greatest specialists and people! The people who believe every

patient is of import and value – role models in their profession! We were overwhelmed with admiration at the attitude, professional qualities, patience and kindness they welcomed us with. Accidentally, during our first stay we met Galya, the contact parent, whom I would like to thank most sincerely and deeply since, before the meeting with the associate professor and his team, she was the one who gave me the hope and courage for a better future! My most heartfelt thanks to Assoc. Prof. Anastasov and his whole team, and to you, Galya! Owing to people like you, our children have the chance of a better future. I truly believe that children like Nicky have been touched by fate and marked as really lucky people, with strong will power and faith in a brighter future; people who deserve to have more than others!

THE STORY OF A.P.

„My best dresses are the ones retailored to my size, and the ones altered: where I have put an element which makes them more interesting and different from ready-to-wear clothes." My son has a scar on his lip, a raised tip of his upper lip and a slightly crooked little nose. He is wonderful. When Plamen was born at Christmas almost 4 years ago, I did not think like that at all but now I am thinking... God is too busy with everything happening to mankind here on earth, so busy that sometimes He cannot finish part of His tasks of a creator and thus puts to the test those with the strongest spirit, ever since their birth. But my son was picked up by wonder-working hands in Plovdiv who managed to finish what was left unfinished. My son is wonderful indeed. The people who share difficult moments create a stronger bond between each other. The ordeal which started the moment Plamen was born reversed the hierarchy of my priorities forever. My lovable son is everything I have and cannot live without. All of us who write and read here are connected in a special way, in the name of our children and their happiness, because of our own fears, but also full of pride of the obstacles we have overcome. I would like to thank all co-creators and co-thinkers for their co-concern!

THE STORY OF P.V.

I also decided to share our story. Why our? Because I was also born with a cleft soft palate and am the mother of a child with the same diagnosis (van der Woude syndrome). It all started back in 1987 when I was born in the maternity ward in the town of Haskovo. The doctors assured my mother I was a healthy baby and everything was fine. When she tried to breastfeed me, she felt there was something wrong but the midwives told her to try again since I was her first child and she had no experience yet. So no one at the hospital saw I had a cleft soft palate. They discharged us and for 20 days my mother kept trying to feed me but I would choke and cry a lot. Finally, my mother reached the conclusion that there was something wrong in my throat, something different from other people's. Then one night she called a midwife she knew, a medical college lecturer, and then the problem became clear. They called the doctor who was in charge of our district and explained everything

to my mother. On the next day my parents took me to the paediatrician, whose care helped me grow as a fairly healthy child without going to hospital (May the sacred memory of Dr Ivan Markov live forever!). He referred them to Assoc. Prof. Chatalbashev at the University Hospital in Plovdiv (I bow to the ground in gratitude to Assoc. Prof. Cahatalbashev, too!). After a consultation with him, it became clear that I could be operated on when I was 2. So my mother learnt how to feed me by making holes in the teat as the doctor had told her, since there were no special bottles at that time. In the course of time both of us learnt to cope with the situation. During those 2 years I learnt to speak. It was hard for me to pronounce certain sounds, such as 'k' or 'ch'. In the early April of 1989, they admitted me for an operation. However, when they took me to the operating room and put me under an aesthetic, there was a discharge from my nose and the operation was postponed. After antibiotic therapy, at the end of April I was successfully operated on (Here I need to thank Assoc. Prof. Chatalbashev and the team that operated on me!). After 7 days in hospital, we went back home. I overcame the difficulties with the pronunciation of certain sounds and managed to learn how to speak well, more or less. Only an expert could find out I had had a surgery of this kind. I have absolutely no memories of what happened then. I had a great childhood, just like any other child's, without any problems at school or university. I graduated, got married and the long-awaited moment came. We were going to have the most precious possession in the world: our own child. My pregnancy was an easy one, monitored by two doctors. I was worried if everything would be fine (organs, systems, etc.). I had a foetal morphology scan and the doctor assured me everything was all right, even more, he explicitly mentioned that the baby's lips were whole. I had no idea he might have a cleft palate since that had not been congenital in me. The great day came: 16 September 2014, when Rossen was born. I had a caesarian for medical resons, so they only showed him to me and took him for the procedures that every newborn infant needs to pass through. On the next day the neonatologist came for a visit. She asked me: "Are you the mother of the baby with the cleft?" I was struck dumb. Although I knew it could be repaired, I was very upset. At that moment they started explaining that the cleft was small, that he would be all right, and so on. However, my heart had sunk. He had to be given antibiotics after his birth (not because of the cleft, but for other reasons), so he had to be bottle-fed. The good thing was he ate from a bottle with a normal Medela teat. Social workers came and so on but luckily no one tackled the subject of leaving the child in a childern's home (this is the most stupid thing, how could anyone start talking you into leaving your child). Anyway, we were discharged and referred to Prof. Anastasov for consultation. When Rossen was five, we were consulted by Prof. Anastasov and his team, very nice people with great attitude and exceptional professionalism. They examined us and explained everything in detail, answering all our questions, then fixed a date for an operation in July this year. When they admitted us to the ward, they gave us a warm welcome and made sure nothing was lacking so that our stay would be as comfortable and peaceful as possible. On the next day they took him for the operation – the longest hour and a half in our lives. I am happy my husband and my mother were able to stay with me. When they brought him back to me, I felt a little better and Prof. Anastasov informed us of the operation. The child went through the anaesthetic well and felt relatively fine. On the third day we were discharged and things slowly took along their regular course. Now, a month after the operation, our son feels well and is a smiling and joyful little boy. We need to have a control check-up and an otorhinolaryngological examination, and I hope everything would be normal. And with all my heart I wish lots of health and professional success to Prof. Anastasov's great team! A huge THANK YOU for everything you do!

THE STORY OF S.T.

It was a hot September morning when, having packed my hospital bag, I set off for my next caesarian at the hospital in Sliven. My daughter, 4 years old at that time, jumped around me, impatient to see her little brother whom we had expected for such a long time. They admitted me to the hospital and the following morning, on 26 September 2012, at 9 sharp, my son was born. I woke up from the anaesthesia with the words: "Is my baby healthy?" and the nurses said I had "a perfectly healthy boy without any problems". Then, of course, I asked to see him. Without any warning, they brought my boy. Still dizzy from the anaesthetic and the post-operative pain, I looked at the small bundle. And then my world collapsed. I was looking at a little boy with huge black hair and a large red hole on the left side of his mouth. I had no idea what was happening. The words "a perfectly healthy baby" echoed in my head, but my eyes could see something was wrong and I did not know what it was. Then the neonatologist came and said the baby had been born with a cleft lip, which was remediable, and the most important thing was that he did not have a cleft palate. So I started repeating to myself that was the most important thing. I burst into

tears and did not know why that terrible thing was happening to me. Where did I go wrong? I had had folic acid and vitamins; I did not smoke or drink, I had a healthy diet, my older child was perfectly healthy. I really did not understand. Later my husband came, who had been told straight after the birth that he would not be able to see us and that they needed to speak to him about something very serious. And, naturally, my husband could not help thinking that either me or the baby had died. But that was not the only inadequate thing at that hospital. Later on the same day, the neonatologist came again and told me she had personally fed the baby with a tube. And I had no idea what that thing was; just imagined my little baby being tortured with tubes. Then I asked: "Wasn't it the most important thing that he does not have a cleft palate?" And then I got the heated: "What do you mean he doesn't have a cleft palate? He has a cleft lip, and a cleft gum, and a cleft palate! You are going to have problems for the next 20 years: problems with speech, with eating, with appearance! Yes! You are going to have plenty of problems!" Then my world collapsed for the second time. Now I really wished that the ground would swallow me up. My husband already knew what had happened and had started searching for information about our problem on the Internet. Before long he found Prof. Anastasov and his team. He phoned Plovdiv immediately and we had a consultation date only three weeks later. A row of nightmarish moments followed in the hospital, including my separation from my child. All mothers had their children brought in but not me. And I was yearning to embrace my little boy who was marked by God in such a way. They would not let me see him or feed him because they did not want to scare the other mothers with my baby. And I was dying with worry that I would go home and not be able to feed him because I already knew he was not like the other children.

And then there was a miracle! The chief neonatology nurse came and showed me how to feed a baby with a cleft. She asked me if we knew about Plovdiv and Professor Anastasov, and told me everything could be fixed, and that the professor would work miracles for us. God had sent me that true, good woman. After my mother-in-law's numerous efforts and pleas, thank God, they finally agreed to let me see my baby and since that day I made sure he was well fed. I would sit there with the bottle hour after hour, and my little starveling would eat everything. So one day they asked me what the baby's name would be. At that moment, all the variants I had had for a name just vanished and I heard myself say: Martin. The god of war! Because my Martin would have many battles before him and end up a winner. After we came home from the hospital, I tried to breastfeed him and in spite of the cleft, he managed to suck. Something my "complete" girl before him had not been able to do! A lot of tense moments followed, filled with much care and a nice, compassionate attitude by Prof. Anastasov's whole team: Dr Gyulev, and Nelly, and Peppy, and all the nurses and doctors in the ward. When Marti was 2 months old, Prof. Anastasov operated on his lip and gum, and at 10 months he corrected his palate. Cannulas, infusion systems, shunts and cardboard boxes on his hands filled that first year of our new life, but with the help of Prof. Anastasov and his whole team, my Martin is almost 3 years old; he looks like the other children and speaks excellently without any speech therapy. I thank God for the wonderful son who taught me I could deal with anything, and every day I thank fate for giving us such an insignificant problem and for making us meet such enthusiastic and caring people, real people: Prof. Anastasov and his team! I deeply respect you and your dedication, and thank you with all my heart for being around and for bringing life back to families like ours!

THE STORY OF M.R.

My story is that when I was pregnant with my baby, I decided to go to a 4D scan when I was nearly in my fifth month, just to make sure that everything was fine with the baby. I went to a very experienced doctor who immediately saw the problem and for a long time wondered how to deliver the news to us. Finally he told us the baby would have a bilateral cleft of the lip and palate. He immediately referred us to Prof. Anastasov for consultation. I spent the remaining four months of my pregnancy in a lot of fear and mixed feelings. I also went to Prof. Anastasov and he assured me that everything would be fine, and the only thing I had to do was have my baby safe and sound! On 20 November 2011, our son Pavlin was born. I knew what to expect – I had read a lot of literature. I also called some contact parents. On 26 March 2012 we had the lip operation, and on the 26 September – the palate operation. Our heartfelt gratitude to Prof. Anastasov and his team! I bow to you!!!

THE STORY OF K.Y.

I am the proud mother of 2 naughty boys – brothers whose difference in age is exactly 3 years and 2 months. My younger son, Ivaylo, was born on 19 May 2013 in Plovdiv, on a peaceful and warm Sunday. The birth was normal, and Ivo was born at 11:25; I saw him and my eyes stopped on his lip though there did not seem to be anything wrong. Even his cry was different but all the doctors said that he was a big and healthy baby (he was born 4.310 kg). The time came for the first feeding and Ivcho would not suck. The doctors said it was my fault, and I was surprised why I did not manage – I had breastfed his brother for 6 months. He could not suck until the end of the day and I had to give him the food from a bottle, but he would not eat from it, either. After he had cried all night long (in hunger), the following morning a young doctor, a woman, came for the consultation. Evidently she suspected something and called Prof. Anastasov, who, luckily, worked upstairs in the same hospital. He came straight away, looked at my little baby's mouth, exchanged 2-3 words with the paediatrician who had called him, then sat next to me and told me the frightful diagnosis: bilateral clef of the hard and soft palate. My whole world collapsed in a second; I had no idea where I was or what was happening. The professor explained everything; he brought me literature to read because I had not even heard of that deformity. He told me everything would be corrected with an operation, that the boy could only have a problem with his speech, but there would be no problem if he saw a speech therapist. That made me even more upset and I cried because the older boy had just begun seeing a speech therapist (he started speaking later). Then I said to myself, "What is this punishment, oh, God, both of my

children will be unable to speak. I only imagined bad things – that neither of them would be able to speak. I was seized by panic and fear but had no choice: I was alone and had to pull myself together for my little baby because eating was the most important thing at that time. They explained there were special bottles and I had to ring my husband to buy some and bring them to me. Yes, but first I had to tell him the bad news, ON THE PHONE at that, the hospital policy was like that, they would not let him in. Generally, he was the calmer one of us both and that was how he took everything. He said that if things could be repaired there was no need to worry so much, there were far more firghtening diagnoses than this one. At that moment he was my sole support. We started handling the feeding, though it was very hard, until a doctor came later in the day and took my child. She said he would stay with them and they were going to feed him, but I insisted that I fed him; however, they said they would not give him to me before they had seen that I could cope, and if he did not put on weight, we would not be discharged. Well, we coped and we were discharged 1 day later than planned. We started getting used to the difficult feeding because my little boy was a fighter. He did not give up, he was stubborn. In the meantime, social workers called and started persuading me to leave him in a home. Their words were: "You already have a healthy boy!!!" I could hardly believe that – how could they even think about that! There was nothing in the world that would make me leave him. I did not think of anything like that, not even for a second. He was operated on when he was 11 months old. I will never forget those 2 hours of waiting, endless, hard. And when I saw him after the operation, with the cannula in his leg and a stitched lip (he had fistulas on his lower lip), I was speechless and in tears. Everything was fine with his palate after the operation but problems started with his ears (they had placed shunts during the operation, but in one ear only – the other one had a narrow canal). Pus formed in his ears several times and he had it removed under general aesthetic. The shunts fell off and were placed back again, then 3 months ago, they were finally removed. We had enough of hospitals, of waking up from anaesthetics... Now, thank God, Ivaylo is a healthy boy who repeats everything like a little parrot even without seeing a speech therapist. I am not very good at writing but I wanted to tell our story in order to give hope and courage to

the families who are now setting off on this hard journey. Hey, people, it is WORTH it, because of each smile of those little BIG heroes. And I am sure that even though God took something away from them, He would grant them something else, more than other people have. And last but not least I would like to say my huge THANK YOU to Prof. Anastasov and his whole team, and to the otorhinolaryngologist, Dr Gyulev. Thank you for being there! Our deepest gratitude for what you are doing for our children!

THE STORY OF I.M.

Suppose two firemen go into the woods to put out a small fire. Then, when they have finished and go down to the river, the face of one of them would be black, and the other fireman's face would be perfectly clean. My question is: "Which one is going to wash his face?" "This is a stupid question. The one with the dirty face, of course." "No! The fireman with the dirty face will look at the other one, the one with the clean face, and will think that he looks exactly like him. The fireman with the clean face, respectively, will look at his colleague and will see his face all covered in black and will say to himself 'I must be dirty, too. I'd better wash.'" This is a story I read in one of Paulo Coelho's books a few months ago. Of course, I could not help relating it to my personal story. The story of how I found out I was different from the others. Some of you have already heard this story from me

personally but I also decided to share it with those I have not had the pleasure of meeting or talking to for longer time. While I was growing up, my parents and I never discussed the fact that I had been born different. I went to school, and I did different things with my friends... I had the happy and not so happy moments in my childhood which are standard for all children. When I was 13, I saw an orthodontist since I had braces for teeth correction. During one my visits to the orthodontist he told me that specialists – surgeons from France, would be coming to Bulgaria to perform operations on "children like you". He did not explain what he meant. But then I went back home, stood in front of the mirror and asked myself: what did the orthodontist mean by "childern like you"!? I felt awkward because I did not know something I was obviously supposed to know. Something I had to find out on my own. Standing in front of the mirror at home, I started examining myself and then I saw it. How was it possible that I had not noticed it before?! I had seen myself in the mirror so many times but I had never noticed there was something which made me different from other people. I will not comment on whether it was right or not that I had been left to find out I had my "distinguishing mark" in that way. I only want to say that we grow up believing we are what others perceive us to be, and by others I mean our closest people, the ones we love the most. This always leads us to the way the "new" people in our lives will perceive us. Am I right!?

The story of D.M.

My name is D.M. and I am Donny's mother – he is a fifteen-year-old Bulgarian boy born with cleft lips and palate. I am also a speech therapist, with a diploma in psychology, and I am currently working at my own speech therapy centre named after him: DOKSI. As a member of ALA, the association of patients with facial anomalies and their parents, I have taken part in various events over the years and will go on being active, no matter Donny has grown up, because I think this is a noble mission: to provide all the necessary information and support to these children and their parents in order to assist their optimal development. We believe each child is unique and deserves a better future, a stable family, a healthy mother, a good surgeon, high-quality speech therapy and psychological support. I have told my story plenty of times and on many occasions, both formal and informal. The story is mostly about the first years, which were

full of drama and tears. Now, when I want to write something, tears are not the most important thing; rather, this is the confidence that I have the say and that things are up to me, that I have walked a worthy way and can still walk. I walked, in tears and foolery, with mistakes and good decisions, with successes and failures… I keep walking. I do not want to forget the tears and the bad things. It is more important not to give them my energy, but to draw on that experience. I cannot live either in the past or in the future. The only moment in time I have control over is the present moment. All others are just sources of wisdom or dreams. I drink from them and move on. What matters is what I can do now, not tomorrow and not what I could have done yesterday. Fifteen years have passed from those heartbreaking first meetings with my exceptional child. Now, when I look back, I realise that what I had considered a punishment had actually been an award. What I had thought was a shame was in fact pride. What I had thought was a disaster turned out an oasis with fertile soil. We are faced with a social stigma that the affected child's mother has done something bad and now has to pay for her sin. I do not think so. We – the parents of children with a problem – have been chosen because we are strong enough to cope. It is necessary to find people like Dr Anastasov, the ALA people, Gareth, Anton and all our friends all over the world who will help us give the best of ourselves. What I want you to remember my story with is Donny's success and the fact that he is an artistic, emotional, curious and lively child who, very energetically but already showing the typical teenager resistance, is developing his potentials. He has diverse interests but his favourite occupation is music: he plays the piano, and he is also the soloist in a vocal group. His last award – the first prize in the Istoki competition in Moscow, was my biggest pride. He studies 2 languages: English and Russian, and is doing very well at school. Last year he won his place in a new school, he managed to find his position among his new classmates and overcome both the ridicule and the isolation. Donny succeeded thanks to the cares of his family and the team headed by Prof. Anastasov. I found that doctor early and we walked a long way step by step to put the child on the international stage. My boy is very happy; I am also happy because I am part of the Association which takes care of children and their families. Sometimes Donny wonders. I wonder, too. How is it possible for anyone, especially a medical specialist, to separate a baby from his or her mother in the 21st century? How is it possible for people to fail to understand simple things like a mother's love, or one's rights to a normal life? My first steps were difficult. During my pregnancy I had had at least two ultrasound scans but the doctor had not said anything. He gave me a cerclage to preserve the pregnancy. I am sure that he knew since after the birth he pretended he did not know me. Perhaps it was hard for him to admit he had made a mistake. The first minutes after the birth were dramatic. They asked me why I did not have an abortion. That was cruel. When the baby comes, you hug him, he cries and opens his eyes. It is impossible to reject him. They left me in the corridor alone, then a nurse came and gave me a pill. I asked if that was for my nerves. She said it was to stop the milk. Trust me, that was a positive thing in the situation. I was mad, it took me out of the shock and I shouted: "Who told you that I was planning to leave my baby and stop my milk?" So they never suggested I should leave my child again but they usually think a mother gives up easily when she encounters a problem. Then they took my baby and I could not see him any more. I had to fight to see my little boy every two hours. First I thought I had to leave the other two boys and take care of this little baby because no one would accept him. But then I managed to pull myself together. I called my husband and we started. A surgeon came and can you imagine what his first words were: “Did no one see this in the scan so that you could have him removed?” At that time it was not possible to choose another surgeon. Sometimes Donny is angry, I am angry, too, because things have not changed much. This happens again but owing to ALA’s efforts, there is already a standard care and reaction procedure. I hope it will become a policy. That is why I take part in ALA’s events and tell nurses, doctors and midwives that the first moments after the birth are the most important ones. That is why I keep working for this cause. As a speech therapist, I could not overcome the trauma I had had at the time of the birth for a long time, so I did not work with children with clefts. But now I can give the best of myself to anyone who comes looking for my advice and help. Donny has his dreams. I have my dreams, too. I dream of creating a network of speech therapists who would help children with clefts throughout the country. I work to that end day after day. I hope to accomplish this but it will not happen tomorrow, just like overcoming a cleft is gradual. What is important is to be strong every day, to keep the negative things away because you cannot fight them. You will always know you are different but there are also many ways of turning difference into success. As a professional, I know our patients are people with real lives, they are not just pictures from medical records, the press or routine daily practice. We are the people who can give the best of ourselves. In 2012, Donny was invited by ALA and our European friends to a meeting at the European Parliament as a child who had received excellent treatment and was brought up in a positive environment. There he said: “The people who mock at me are people without hearts. I have a dream: to become a pilot and to sing. Like Mom, I also like this wise thought: ‘We cannot change our destiny but we can really change our attitude to it.'" At that meeting, he talked to everyone, he told jokes, he showed he was a happily communicating child. That was my reward…

Donny at his European Parliament presentation.

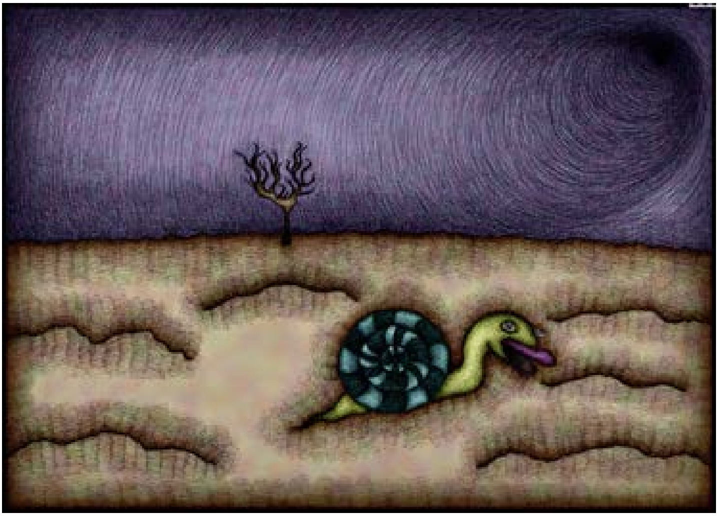
Postscript:

The My Story competition ended. The story told by J.I. received the most likes and won the first prize: an honorary diploma and the sum of 500 Bulgarian levs handed in at ALA's General Assembly on 10 October. Here is J.I.'s answer:

"With all my heart I thank everyone: friends, people I know and those I do not know, for voting for our story. Although I was unable to personally experience this emotion due to health problems, my husband and the main character in the story, Bobby, were at the ALA event. We never hoped to win the first prize since all stories were equally exciting. The story I wrote was about what we had been through, and it was not written for the award; I just wanted more people to read it and realise that the children with facial anomalies are not second-hand, to realise that a lot of patience, effort and plenty of love can turn such a child into a beautiful swan. We were never tempted by the award and had made a decision to donate the money, if we happened to win it, to the association. And so we did. The prize today was a donation to the Association of Patients with Congenital Facial Anomalies and Their Parents, or ALA. I know and I am sure that the money will be used wherever they are needed in the best possible way. Dear people, love your children, be proud of them and surround them with a lot of love and patience.

J.I."

The Board decided that the remaining 1500 levs be divided among all the other participants. Some of them gave up their awards donating them to ALA, and we are really grateful to



them for that. Some refused to have their stories published in this booklet and we respect their decision. We thank all the participants, and please be ready for dads' stories next year...