

ADITYA CASE STUDY

Birth Defect: Q75.4 Mandibulo Facial Dysostosis, Q35.9 Cleft palate unspecified Q72.4 Longitudinal reduction defect of femur, Q21.1 ASD, Q21.0 VSD`

My name is **Neha (Second Gravida)**, I got married on **15th of February 2015**. Before Aditya I have a son who was born on **18th of February 2016**, now he has turned 6 years old. I have **never had any abortion before Aditya and elder son “Kavish”**. My elder son was also born through **normal delivery in Chandigarh Sec 22** and he **doesn't have any kind of problem** and is very **intelligent**.

In the beginning of Aditya's pregnancy, **till 3 months we did not know that I was pregnant**. Even if there were symptoms, they were ignored because my elder son was also very small or at that time and my periods did not even come till 6 months and Aditya was conceived. A doubt already came in the beginning because **I felt a little dizzy but vomiting or nauseous feeling was not there**. In fact, during the time of my elder son, **my health was worse, I had vomiting and used to get dizzy or sick a lot**. But at the time of Aditya, **I did not have any symptoms** so we did not know when I conceived, then I checked with Prega-news kit, then both lines were showing clearly, Then when we got the ultrasound done, I came to know that **I am 4 months pregnant**.

I had decided to abort my second child because my eldest son was **very small or not even 1 year old**, he used to breastfeed **too** and my **family members also agreed for abortion**. So I went to the doctor for abortion and he said that you have come very late. Secondly, now your pregnancy has started 4 months, so now you and the child may be at risk, so the doctor refused for abortion and said you should continue your second pregnancy as well.

In the whole pregnancy, I got **2 Ultrasounds done in the 4th and 7th month**. Because I didn't get to know about pregnancy till 3 months or as I **didn't even take Calcium, Iron-Folic Acid in the beginning** so the

doctor was worried and had doubt that there might be a defect in the child, than he advised us for **colored ultrasound in the 3rd month itself**, the doctor felt that the child is weak and if there is any problem or defect in the child, then it will come in report, but when I came to know about pregnancy then **I started all necessary medicines from 4th month** but due to any reason we **did not able to get the colored Ultrasound done**.

My **1st Ultrasound done in 4th month** and I showed to **Sai Hospital (Ambala)** then **Second Ultrasound** was done in my **7th month** for which I went to **Chandigarh** because my first child was born in the same place, so I wanted my second child to be born in the Chandigarh and it was also in mind that the facilities in Chandigarh are also very good. In both the ultrasounds, the **doctor did not tell us anything that there is any defect** in the baby.

My **complete routine checkup was done from Chandigarh Sec 22**, from where doctor told us in 2nd ultrasound in 7th month that you will have a “**Breech Delivery**” because “Aap Ka Bacha Ulta Hai”, when I heard about the **Breech Delivery** I got “**Tensed**” that the delivery would be **through C-Section** and the doctor also told us that “Bacha Ulta Hai To Kuch Bhi Ho Sakta Hain”. The doctor also told us that even if the delivery is normal, there could be a risk to the life of either the mother or the child. A lot of thoughts were coming in my mind but because I had **started to have pain at home so we went to Chandigarh Sec 22**, than from **Chandigarh Sec 22 doctors referred us to Sec 16 (GMHS)** for delivery. Because there was a lot of risk in breech delivery, they also made us sign on consent form that if something wrong will happened we will not be responsible and assured us that we will not do C-Section, the child is being delivered through normal delivery but if anything happened to anyone don't blame us but everything was fine with God's blessings, and on **11th of May 2017**, I gave birth to a **baby boy by normal delivery**, at that time the child's weight was **2 kg**.

Father told me that the **delivery was done even before I reached Chandigarh from Ambala**. When I came to know that there was another son too we were very happy. Then **after 10 minutes** the doctor called me

and said that this is the condition of the child and **there is only 20% chance of his survival** because the child was having **a lot of breathing problems** and I also saw that **lot of blood was coming out from his mouth**, they also said that the child has a **short leg and a hole in the mouth as well**. Doctors were also told that there is a **hole in the child's heart too**, but there is nothing to be worried about because the **hole is minor and it will fill itself in 2 weeks**. Because the condition of the child was very bad, the doctor asked what your decision was, then I **asked the doctors what you can do from your side and how many chances there are for the child's survival**. So the doctor said, we cannot say anything. Trust me I couldn't control my emotions and started crying and then I told the doctor to **do whatever is best for you and if you need anything, then please tell me because I want my child alive**.

Father said **many things were hitting in my mind** that first we thought of abortion but as “Hum Baccha Girwa Ke Paap Nahi Karna Chahte The” so we did not get abortion done and now when the child was born which was not expected, we tried our best to make the child survive. Then the **doctor sent the child to the nursery within half an hour and put him on oxygen**. As long as the child remained in the nursery, all the checkups and tests of the child were going continuously.

Mother said, I still remember **when I was shifted to the ward**, my mother came to me and asked Neha, are you fine because **I had also got 4-5 stitches**, so I said yes, I am fine and she said **you delivered a baby boy**. At that time mother knew the condition of the child but mother did not want to tell me till that time. Because they felt that it was not the right time to tell the child in this condition. For **2 days I did not know that there was some problem with the child** because no one had told me. I used to ask many times that where is the child and when they will give to me, then they used to say that the child has on oxygen, so they kept him in the machine, he is fine, you please do not panic he will get well soon and said, **they will give your child in the evening, then the day has passed. The next day has also passed**, I will be worried whether he will give it to me or not. This

was the tension of when I will feed him. The other day **my mother used to tell me that there is some problem in the child's body, but no one told me about it properly.**

I still remember that the next day of delivery the nurse came to me and asked my name, are you the mother of the child? Then she told me to get up and feed my child so I said ok and I **walked comfortably from the ward to the nursery** because at that time **I had stitches in the delivery.** When I reached the nursery, I started searching where my child was, then I saw that my name Neha was written on the hand band of the child, my husband's name was also written, then I got to know that this is my child. When I saw the baby, **the baby was lying on his stomach** “Ulta Leta Hua Tha” then **I asked the nurse why the baby was lying on his tummy?** So she said that there was a problem in breathing that's why he is lying like this. I got “**Scared**” and asked “**Madam Mera Bacha Thik To Hai Na**” then the staff said don't worry, your child is fine.

After reaching to nursery, **staff asked me how you will feed to your child** so I said **I will feed the way everyone feed.** Then I sat down and hold the child in my lap and **I noticed that the child was not sucking my milk.** I started thinking that why he is not drinking my milk, then the nurse came to me and said that he will not drink like this, **he has “Palate”.** I **start thinking what it means** because I **did not understand what it does mean Palate.** Then the **staff came to me and open the mouth of the child** and said look, many children have a problem like this. Trust me when I saw child's Cleft Palate “Madam Mere Pairo Ke Niche Se Zameen Khisak Gyi”, I could not understand anything what is happening. Then the doctor came to check on the round and asked Neha, is this your child? Then I said yes, than am sure you must know what problems your child having. So I got scared that what are the problems Sir, so they explained me the condition, at that time I kept looking at the child that he has so many problems. After hearing everything what doctor said, I don't know what happened and I became fainted. I was so **worried and asked the doctor, Sir, will my child be cured?** So the doctor said that his oxygen level is fine now, the rest will get better as he grows up you feed him now, then I told him how do I feed him, he is not able to do it. So the **doctor said that express your breast milk in Katori and fills it in a syringe**

and gives to the child through the pipe. Doctors advised us not to feed much, so we used to give only **5-10 ML to the child.**

Even in the hospital, I used to face a lot of trouble in feeding because most of the time he used to pump out the milk so the staff used to tell me to hold the baby on shoulder, so after feeding I **always used to give a tap on baby shoulder to make him belch.** Mostly whenever I feed the baby, **milk used to come out from his nose,** so I used to ask the doctor why this is happening, then the doctor made me understand that till the child's Palate surgery is not done, the child will have the same problem. **Many times I used to get very scared because the milk used to come out much more than I feed.** At that time there was so much tension in the mind because the way his condition was, it used to think whether he would be able to survive or not. Because I have faced that problem, I only know. The **staff was very cooperative** whenever I felt broken, **the staff and doctors used to understand me that you have to be strong.** You will have to face such problems you do not have to be afraid at all or whenever there is any problem in feeding at home immediately you need to contact us to avoid any kind of tragedy with the child and make sure just don't force your child to feed as he is not good to digest.

Mom said that I remember because there was a problem in feeding the baby, so the staff told me about the Pigeon **bottle, the nipple of the bottle was too long** and the **staff said that you have to take out your breast milk and give it to the baby through this bottle.** Because he is not able to suck or hold the nipple from the lips, then through **the bottle feed will go straight into the child's stomach.** The doctor also advised us to feed the baby **little by little** and at that time the **baby's head should be straight.** All the doctors and staff in the hospital were so cooperative that whenever I used to feed the child, the staff used to be with us whether I was able to feed properly or not and also used to say **that if you are facing any problem in feeding then do not feel sorry, we will help you to give milk to the child.** I was always worried while feeding the child that if some mistake might happen, the baby can be hurt. Because **I badly wanted to learn how to feed the baby, so within 2 days I got**

trained in observation of staff and doctors and I used to **feed only 2-3 times** because **the doctor told me not to feed more because the child was unable to digest**, then we always used to give the milk in less amount.

Then when I had **the command of confidence that now I can feed** so I requested the doctor to send us home because now I **don't even feel good being in the hospital** and I want to go home because at that time I was also staying in the hospital. All this was in my mind that **when I will take the child home, how will I manage? How will the baby survive? Will he be okay or not?** Because of the condition I saw as he suffered in the hospital, we used to think about how we will take care of him so **there was a lot of negativity in the mind**, but motivation was also there from the **family or husband too because everyone was very supportive**. Then on request the doctor discharged us and told us that you will have to do child follow up from the PGI and then they referred us **from Chandigarh Sec22 to PGI**. Then **after 10 days of being discharged from the hospital**, we came home because by then he had started **taking my feed comfortably and the problem in breathing was also cured**. The next day in the morning we went to PGI with the child because we **had to get information about the leg of the child and also wanted to know about his Cleft Palate surgery**.

When we reached PGI, first of all they made the **child's card and checked the child's height and weight**, then asked what the problem was, and then we told them everything, **at that time the baby was only 11 days old**. Then they were suggested that you have to **go to the Cleft Palate Doctor, Orthopedic Doctor and Genetic Doctor as well**. Then we searched on **which day the Doctor sits in the OPD and according to that day we had started the treatment** of the child. Firstly we showed our child to **Dr Inusha in Genetic OPD on Thursday**. Because the child's complete checkup was done there and **she checked the child's joints, checked the child's marks** and later she discussed with her assistant doctor that wherever there are problems in the joint, there will be marks. the doctor told us that the **child's hip is very big and the hip bones are in curved shape and have minor marks on both sides of the pelvic bone, one leg is smaller and the other one is bigger**.

Overall, the doctor had explained everything to us and he guided us to go to the Orthopedic Doctor. Which doctor we have to go to, everything was guided by the **Doctor of Genetic OPD**.

The mother said that **the child was shown in almost all OPDs so that there is no ignorance in his health and treatment** of the child. **After the Genetic OPD we went to the Ortho OPD** because **all the doctors were sitting on different days**, so we used to go to the **Ortho OPD on Wednesdays**. When we showed the child to OPDs he was **very small and just 12 days old**. The doctor got the child's X-ray done and after seeing the report he said that the **child's leg bones are bent** and the **child's femur bone has not been properly formed, it has not grown well**. The doctor was very good and calm, **he checked all the joints of the child by lying him down and tried to pull the child's joints and saw**, at that time the **child was crying a little and his facial expressions were like what are you doing with me because he used to get scared that time**. Then the doctor said the child will have surgery because it cannot be **cured even with plaster because in plaster the bent leg becomes straight** but in your child's case his **bone is small, there is no growth, so the operation is the last operation**. When we asked him about the operation, the doctor said that he is **very young and weak too, so let him survive**. When the child grows up, we will talk about the operation after seeing the condition and the Doctor said whenever we call, you will have to come for follow up.

Mother told me that I had many questions, so I asked the doctor **whether my child would be able to sit or not**. So the doctor said that **there will be no problem in sitting**, but the child may **have some problem in walking** because the one leg is very small so there may be **a problem in making the balance**. He also **guided us about artificial shoes** and said that a child **has to wear artificial shoes and to walk daily** only then the child will **develop the habit of walking with shoes**.

We used to **go to the ENT OPD as well** on Tuesday **for around 2 months**. Whichever doctor says go to this department for this problem of the child So there were many OPDs and departments in which we went 3-4 times whose names we do not even remember now. Whatever Dr. used to say, we used to go there that time.

Because when the child was born, there **were holes in the child's heart, so we also went to the Cardiac OPD**, there **ECG was also done**, but everything was fine. We also took the child for an **“Eye Test” whether there is any problem in the eye? Is he able to see properly or not?** We also went to **Neuro OPD, Brain Tests were also done** to see how the baby's mind is, **mentally retarded or not?** But everything was fine, whoever guides us, wherever tells us to go, we definitely go.

Father said that the doctor had also advised the child for **Physiotherapy. Friday or Saturday, for 2 days in a week physiotherapy OPD was there** and for few days I also got the child's exercise done in OPD then later I requested the doctor that **I can get the exercise done at home** because we have to come from far away and it used to **take us 1.5 hours to reach PGI from home**. From the time the child was born till now, we used to go to **PGI regularly for follow up for 3 years** because we did not want to miss any OPD of the child.

Father told us that for **routine checkups we used to go to PGI twice in a month**. I still remember that the **doctor of Genetic OPD gave us a date** that we will do the operation of the child's **Cleft Palate in April**, then they admitted the child on **1st of April 2018** and on the next day, **2nd of April 2018**, the child's cleft Palate was operated **at PGI Nehru Hospital**. At that time the baby was **11 months old**. There is an organization, they had ordered some equipment, in which there were pipes, probably the cost was **1100 rupees**, apart from that we did not have any expense on operation.

After the cleft palate operation when the child was **1.5 years old**, we went for a follow up, then the doctor **gave us the address that went there and by giving the size of the child's shoes they got artificial shoes from there**. Then we went to the same address. That time **shoes cost 9000 rupees but all our money was wasted**.

Because our **child was very weak and the doctor had made the shoes very heavy**, the child could not balance himself. Whenever we used to put on shoes and walk, the child **could not stand properly and used to fall** because he was not able to **balance himself at all**. At that time we used to allow the child to wear **artificial shoes in one leg and normal shoes in another leg**. As the child doesn't like to carry artificial shoes so whenever we used to wear shoes, the **baby became very irritated or started crying a lot and requested us to remove them**. The child used to **wear shoes 2 times a day** when we used to go outside in the morning and evening **only for 10-15 minutes** and trust me it was very difficult for us to handle him because he used to cry that time very badly. **Many times we tried to force him or to distract him so that somehow he would carry shoes** but he used to get very irritated. We only **wore them for 2-3 months**. While carrying the shoes we noticed that it used to **scratch the child's leg and he complained of pain in the leg** and we used to understand that the child is having a problem so finally we refused to carry shoes.

So far we **have made 2 shoes for the child** because the first shoes were not well made; Then we **again went to the doctor** and told that the **child is facing a lot of problems due to the shoes** and requested for **light shoes**, then the doctor said that the **size will remain the same** because only then the child will be able to balance. We requested the doctor to make such shoes that the **child may feel comfortable to wear**. Because whenever we put on his shoes, he comes to know that **I am wearing something else in one Leg and something else in the other** and then he gets irritated even more, so the doctor **made a fake foot for the second time**, in which the **lower foot was artificially made and over the artificial foot the child kept his foot for support or balance, at that time the child was 2 years old**. I still remember, at that time the cost of **second shoes was around 10000 Rs** which was **more expensive than before**. But the problem happened when the **child did not even wear the second pair of shoes too**; he **hardly wore it for 3-4 days** and we kept the shoes like this at home. Then we also **did not force the child too much, we thought** that when he does not want to wear it then

why get it made because the cost was also very high and the child also used to bother me a lot, and we noticed that **without shoes he used to be happier and feel free.**

After February 2020, we did not go for the follow up because of the lockdown. We remember that the Genetic Doctor had also called us to do the child's "Gene test" and the **cost of that test was told to us 25,000 Rs** in which it will be known everything that **why the child is facing so much trouble, like why there was a problem of cleft palate, why there was a hole in the heart, Why the problems came in the bones**, then we will know everything from this test and it will also be **confirmed whether there will be any problem in the future or not** and yes that test was very expensive. The child's blood test was done in PGI itself but the sample had gone somewhere outside. **But till now we have not taken the report** of the child because Corona lockdown happened, we tried a lot to get the report even through the phone or on whatsapp but the doctors did not talk to us and we have thought that whenever we go to PGI, then we will take the report because now it is already too late.

Mother said that even before the operation of Cleft Palate, she faced a lot of trouble or many times she used to cry continuously while feeding the child and said I always used to carry a lot of hanky to wipe his face and the child also had the problem of **constipation for 3 years.**

Because the child was **undergoing speech therapy for 3 years** and the therapy started **even before 6 months of lock down**, after Lockdown we talked to the doctor because our **focus was more on the child's speech**, so the **doctor gave us his number** and used to talk to us over the phone. The Doctor said that you can **keep the child's speech therapy continuous even at home.** He said that if you **send me small clips of the child's speech, then I will guide you by watching the video of your child.** In the beginning, doctors used to follow us, used to give responses also but then after some time they also stopped responding. We **continued the child's speech therapy for 10 months**, then after that we started to educate and **teach him 1, 2, 3, 4** but due to

the problem of cleft palate, the child used to have a lot of problems with speaking. Rather, there are still some words which even today's children **cannot speak clearly, especially "R"**. In the beginning too, children used to say **"Ka " as"Ta " and"Ch " was also called "Ta"**. The child had a **lot of difficulty in saying "pa"** as well, the word **"pa" could not come out of his mouth**. Whoever's name we used to call, **whether dada or dadi he used to call everyone as "mama"** he used to call father as "mama" too. The doctor had also said that until the child starts speaking clearly, his speech therapy should be continued. We also know that **whatever improvement has come in the child today, it has come only because of speech therapy**.

Even today we are doing therapy for the child at home, the doctor told us that **"Bache Ko Jyada Se Jyada Funk Marwani Hai"** so we force the child to **inflate the balloon, light the candle and repeatedly tell the child to blow it out, tell him to blown the bubbles** by himself so that there will be an exercise of his mouth because even the chin of the child was not made proper. So Chin will also grow due to this, the doctor said that **the more you do mouth exercise, the more the child's mouth will open**.

Mother said that the child **started eating properly from the age of 3 years** and I had given my **breast feed only for 2 months** and **after 14 months we started giving Khichdi, Porridge** to the baby. As the child didn't know how to eat, we used to **grind all the things in the mixer and make a thin paste** so that he can easily swallow. But now he eats everything well and if his favorite vegetable is made, then he eats 2-3 chapatis easily.

The mother said that the child **does all the work on his own** but there is **some problem in eating** as the joints of his **hands are not fully open**, so he eats food by holding a spoon and the whole hand has to be rotated in the C-shape because his hands cannot be straight. The child tries his best to eat by himself.

Now we have to start the routine checkup of the child's follow up as it has been delayed due to the lockdown. I also **do massage of the child's feet** but due to being busy many times, I am not able to do the

massage. I have a **joint family**, my **husband works in a Pharma company** and so far **around 80,000 rupees have been spent for the child's treatment** including the entire test and shoes cost.

We **didn't face much problem during Covid** but because my husband had got Covid so during that time we faced some problems. Father told me that **in August 2020 I had got Covid**, that time I became **tense and panicked** because in those days I used to live near my family and Aditya also used to sleep with me. In those days, I had also received a call from the hospital, but on my request, I **was under home quarantine**. The best part was that all the **other members in the house were fine** and all the **neighbors and relatives also supported us a lot**.

Mother said that there is a **lot of love between both the brothers**. **Kavish is a very sensible and calm boy** but **Aditya gets very angry soon** and even **hits Kavish** or as long as I do not stop he keeps on hitting him. When Aditya was small, Kavish used to **ask my mom why my brother is like this, why is his leg so small so I used to say that when he grows up, then he will be fine**. Because Kavish has a **lot of patience** and he understands that Aditya is my younger brother he **takes full care of his younger brother** and if anyone says something wrong to Aditya, then Kavish interrupts everyone.

We have **never received any kind of discrimination from family and society, even if everyone takes care of him**. Someone is always with him if he plays outside or goes to someone else's house or until he will not come back home **someone keeps standing and observing him until he reaches home**.

Aditya likes **“Aalu Ki Sabji”, “Rajma”, “Curd” and “Dal Roti”** in food. At home, we also make **“Panjiri”** and give it to the child. He **likes sweets a lot**, especially **“Jalebi”**. He also likes **“Dry Fruits”** very much. There was **no complaint even from the school** but many times the teacher could not understand what Aditya says because he has a problem **in speaking some words** but when **she listens carefully then he understands everything**. Baby speaks **A, B, C, D** and can also **write it in cursive**. Aditya is good at studying

and rest depends on his mood; **sometimes he gets good marks, sometimes less** but we never forced him to study.

Father said that **we are worried only about the legs** of the child as the doctor had told us about the surgery but we were not satisfied after hearing that **“Bache Ki Leg Ko Ulta Karke Laga Denge ”**. So we decided that we will think about the surgery **only after 15 years**, till then **we will let the natural growth of the child happen** and for **hands or joints we will continue to do the exercise**. In the exercise session at home, we **rotate the child’s right hand in a circular manner for 10 times and the same on the left side in a circular manner for 10 times** and if I am busy then someone else in the house will do the exercise.

Father said that there is **not much plan for his education in future**; rest depends on the capacity of the child and the rest we also think about the **handicap quota from the government**. The only thing is that the child should study well so that he can go ahead and **get a government job through handicap quota**. But we do not put too much burden on the child; the rest is up to him, if he studies well till the age of 10 or 12. We haven't thought of anything like he has to **become a doctor or an engineer** yet.

Mother told that the child is **good in all physical activities like walking, running does everything well, “Sedi Chadna or Utarna”** does everything comfortably but he **becomes tired quickly**, many times he will keep on playing, so we stopped him and say that Aditya get some rest but he never listen.

Mother said that even at home my family members and some of our relatives asked me whether there was **“Grahan”** during Aditya's pregnancy or maybe due to the **“Grahan”** there was a problem in the child. He used to say many other things but I used to ignore everything because I remember there was **“Grahan”** in the first pregnancy and I **had also paid attention** but at the time of Aditya, I do not remember whether the **“Grahan”** came or not.

In the village, everyone used **to tell many tricks or solutions** that whenever there is **“Grahan”**, at that time, **take the child out of the village and cover his half of the body which has a defect in cow dung or grass** or **when the “Grahan” ends, take the child out from the cow dung or grass**. But we did not believe in these superstitions and used to ignore them because everyone used to say something so whom to listen. Some even used to say that during the **“Grahan”** the child should be bathed along with the mother and some also used to say that if something happens in the **“Grahan”**, then **there is no solution for it**, but we did not listen to anyone. Today our child is **5 years 8 months old**, we all love him very much and we are very happy.

I am a member of **“Divyang Shakti Group”** and I follow whatever is suggested in the group and I also share the **photos and videos of the child's activities in the group**. We are taught a lot in the group and I also talked to **Satvinder madam**, she **guides me about the diet and weight** of the baby and I like the way Dr. Vijay Kumar guides us which really helps me a lot.

THANK YOU!