

Devna's journey

Mother Mamta, father Sudesh got married on 3rd December 2014, mother conceived in January, antenatal treatment and check ups were being done from Usha Rathi Hospital Yamunanagar. 2-3 months everything was fine, 5th month ultrasound diagnosed Hydrocephalus "sir me pani" in the baby. The Doctor advised that it is moderate and will become okay with surgery, no other problem was detected. Consultations were done and no other problem was recognized. Mother was admitted in Usha Rathi Hospital Yamunanagar for delivery and the family left it to the Doctor whether to conduct a normal delivery or a cesarean section. The Doctor conducted the check up and as there was no other problem detected she decided to conduct a normal delivery. Baby girl was delivered on 28th September 2015 Monday at 1.30 PM. The family did not know about the Cervical meningomyelocele ('gardan me phoda") or the Lumbar spina bifida ("kamar me phoda") which burst on delivery. Father was called and he was shocked and grief stricken to see that there was a tumor in the lower back which had burst. He saw a small open tumor in which the nerves were entangled with each other. He was counseled by the Doctor that the baby can have problems as the congenital anomalies were not detected in the ultrasound during the Antenatal period so she was referred to the PGIMER for treatment. The family stayed overnight in the private hospital and the dressing was done by the staff. In the morning they took the baby to PGIMER via their home to enable them to pick up their clothes and other essentials for the stay in PGIMER they reached PGIMER on 29th September and Surgery was done the next day on 30th September. The surgery took 3-4 hours and both the congenital anomalies were repaired simultaneously. Mother was at home post delivery and she was called to PGIMER to

enable her to feed the baby and care for her. Devna was unconscious and sedated after surgery for one day, the family members were living in the PGIMER as attendants for 7-8 days as the baby was in the Emergency. After that they were discharged from the PGIMER for follow up and stitches removal after 7-10 days. No dressing was required to be done before stitches removal. She was called again around 17th -18th October and further called again after 10 days for a follow up CT scan as her head size was increasing due to fluid build up as she had been diagnosed as having ante natally recognized moderate non-communicating hydrocephalus. The hydrocephalus was managed with medical treatment by Doctors, initially they said that surgery will be done but they treated her with medication. CT scans were done monthly and bi-monthly to monitor progress her Hydrocephalus was cured in 2017 during treatment she used to remain drowsy due to the medication. Devna was paralyzed below the waist and could not walk. At birth she was given an injection in her feet maybe for Tetanus and she started crying. In PGIMER also they took her blood samples from the feet with great difficulty, and she used to cry as repeated attempts had to be made to get the blood samples. Father used to work in a Private medical firm but had to take leave for her treatment, he saw that their baby was unable to move her feet post surgery. There was no sensation in both her legs up to the knees post surgery but now in her left foot on pinching there is some response to stimuli. She has some sensation and feeling of itching, something is happening there for the last 7-8 months in the left leg. The right leg still has no sensation. Her feet remain pointed outwards when she walks. Post surgery both feet remain pointed outwards, the parents try to keep them straight but she

is unable to. Devna could not walk or stand and there was immense tension and stress in the family.

Physiotherapy was advised for Devna, Civil hospital Yamunanagar being far away, she was taken to the Government hospital at Sadaura which is about 15 Kms. from their village daily for physiotherapy by her father on the motorcycle. He was working in a Private company and used to come home at 5.0 PM and take her to Sadaura, they used to come back home at 8.0 – 9.0 PM at night. One day in a hurry to get home my father had an accident on the way home from work on the Motor bike and broke his knee. The Physiotherapist agreed to come home and provide exercises, movement and pressure point therapy to stimulate the nerves. Electric current stimulation was administered in the muscles. The Physiotherapist stopped coming after some time as he also had personal problems and wanted more payment which he was offered but he withdrew his services. Father took her to M.L. civil hospital Yamunanagar where she was prescribed movement, exercises and special shoes. Special shoes were made from PGIMER at the age of one and half years to 2 years and they were changed once she outgrew them as they were restricting the blood circulation and her legs will become bent and restrict growth. Exercises were advised.

The expenditure on Devna's surgery, medication tests and travel were as detailed. One surgery was done and the expenditure came to Rs. 30,000/- in PGIMER. Travel to and fro cost Rs. 2000/- per trip and in the 1st year 10-12 trips were made monthly and bi-monthly sometimes they missed her follow ups later on they went only 4-5 times a year due to problems at home. Their grandmother was operated for her hip problem " Kulhe ka gola" . She could not walk and was in a lot of pain, so they could not devote time to Devna as there were problems at

home. Then they had a second pregnancy and Shivansh was born and they could not go to PGIMER for follow ups. Now they will go to PGIMER for follow ups as the Doctors also enquire about her. Shivansh was born on 28th September 2020, Monday and coincidentally the Father, Daughter, and Son all three have the same day and date of birth. Physiotherapy cost Rs. 50/- at Civil hospital Sadhaura but at home he was charging Rs. 100/- per visit daily till 2020. Physiotherapy continued from April 2016 to December 2020 as the parents said “ Bacha kamyab ho jaye humara”. The father was in a Private job at that time but was part of the layoffs during Covid lockdown. The family has a “ Karyana" shop in the village and they have support from the family and the father works at the shop but is M.A. Sociology and giving exams for Government selection exams. He is unable to study due to time constraints which are devoted to Devna’s upbringing. He is looking for a Private job so that he has financial support.

Civil hospital Yamunanagar advised them to get an MRI done, Dr. Raj Neurologist in Yamunanagar also advised MRI although he said I can not promise anything. A vehicle comes from General hospital Panchkula to M. L. civil hospital for MRI which is free for them as he is of Scheduled caste but they could not get it done as the machine makes noise and she used to get scared. For 5 -6 days they spent residing with their sister and went to the General hospital whenever the Doctors called them at night also. The Doctors could not sedate her and could not find her veins for injection, she used to wake up as soon as she was put in the machine. Devna’s MRI can be done in PGIMER only as the Doctors will be there to supervise her as she will be unconscious and in Emergency. Doctors have advised MRI to ascertain if at all any treatment can be done. The winter's come and now they will get it done. In winters she

faces problems in exercising and practicing walking. Dr. Vijay Kumar Swach has given good guidance and advice which the family followed regarding the special “Walker” to help her practice walking and she also has special “Shoes” which help her to stand and so that she does not fall down and has control. The parents are searching for the “Walker” supplier and will buy it soon. Devna has no control over her urine and stool and the family is worried about her all the time when she is in school. She wears a diaper to manage the problem of leakage of urine. She changes 2-3 diapers in 24 hours. They make her pass urine before school and after coming home from school. Doctor has prescribed medicines for urine control. She passes stool at least 1-2 times daily. A special standing seat has been made for her toilet needs. The parents get stressed out because she is a child. Doctors have prescribed clean intermittent catheterisation (CIC) and the mother does it 3 times daily.

The parents dream for Devna is that God has gifted her to them and they can not do anything about her problems but if they can get help and guidance in caring for her and bringing her up it would be great. They desire that she is literate and goes for studies, she is self sufficient and not dependent on others. She is educated and gets a job. She gets treatment and can manage to recognize her toilet needs at least. She is able to walk with support. She has been wearing diapers since 2015, and gets ulcers “Jakham “ due to continuous diaper use in the groin area and sides in the waist. She gets allergies so it is very difficult for her and causes her stress. They are caring for her and looking after her needs up to their maximum capacity. The whole family is focused on her needs and providing her loving care and support. She got 1st prize in the District on 15th August dance competition sponsored by a sansthan

in Yamunanagar. Father has shared her videos in Divyang Shakti above the 3 years group.

Devna was given exclusive breast feeding by her Mother for 6 months and continued supportive feeding up to two and half years. The Doctors discouraged her mother after 6 months but she continued as Devna insisted on taking her Mothers feed. Shivansh has also been provided exclusive breast feeding and continuing up to two and half years. After 6 months “Cerelac” was started and she started eating foods like “Daliya”, “Khichdi” and Rice etc. Shivansh cries for mothers feed has food but is a little irritable. Father says he is a little weak also he does not have a good diet and does not eat well. Devna has a good appetite and the parents tell her to eat less because they are worried her weight might increase. She does not have fruit Shivansh has apples and Banana. Devna says she does not have it because her Mother does not give her although they are kept in the house. She forgets to ask her mother to give her fruit. Father says children eat less in winter. Devna says she will go home and eat Banana. Day before yesterday she had “Sag”. After having food she sleeps some days, if she does not sleep she plays alone or with Shivansh then afterwards she does homework of School. Then she goes “ghumne dukan par” she goes on a cycle with “Papa”. She plays at the shop then comes home and does homework of School. The family has a “Kiryana” shop in the village. Then she plays with her brother. She has dinner at 8: 00 PM “Roti” “Sabji”, and has milk at night in one glass. If she has a cold she does not drink milk. She sleeps at 10.0 PM, she can tell time, she has recited her daily routine on being asked specific questions. She watches TV at night, she sleeps with her “Amma ji”, since Shivansh was born as it is too crowded in the bed. “Amma pe hi sona he bhid hoti he”, “Amma akeli hoti he dar lag jate hai isliye hum

ikathe hi sote he". Everyone loves her at home, in the neighborhood and in the School. The teacher in School scolded her and "thappad shappad marti he dande nahi marti" "pyaar se marte he" over homework. At home when she makes a mistake "galai" they scold her lovingly " pyaar se marte he", but she does not get angry. She fights with Shivansh and he also fights with her then both of them get a scolding then they start playing again.

The father is 5 feet 7 inches in height and the mother is 5 feet 3 inches height, Grand parents are 5 feet 6 inches height.

There is no tension or problem in the house because of her physical disabilities. Devna is happy to go to School, no body troubles her in School, children or Master all the children love her and the master also loves her nobody says anything to hurt her feelings. She is studying in 2nd class, she says she is good in studies and she stood first in 1st class. When Devna comes from School she wears the special "Shoes" but does not wear them in School. At home they make her practice walking, father has made a special "Stand" for her in which she can stand with support. It is welded and fixed to the wall. Father has shared the videos in the "Divyang shakti" group for over 3 years. They put her in the stand, she can stand there and conduct her activities. She can bend also. She sits cross legged. She practices walking with support between two folding "Manji" backward and forwards with hands support. Hands exercise is also being done to strengthen her hands to enable her to support her weight with her hands so that she can move around with support. Practice is ongoing. The Doctor has advised two pillars but yet they are using two "Manji". She has a walker also with which she can walk with support. She does not wear shoes all the time as she gets sores because they have to be tightened. At night if she wore the

“Shoes” she used to get sores so it was discontinued at night and in School. They used to take them off in the morning at bathe time. The sores used to get infected and became bigger so the Doctor said okay but during the day wear them for at least 3-4 hours or more daily so that her legs remain straight. Her shoes have become smaller now so they will have to get new shoes made from PGIMER. She has changed shoes once which became smaller from the knees now again she has outgrown the “Shoes” from her knees. The first pair of “Shoes” cost Rs. 5500/- , 2nd pair cost Rs. 7000/- now let's see what the 3rd pair costs. There is a sansthan in Ambala which makes “Shoes” and provides them free of cost. Right now exams are starting so after that they will get them made. They are looking for financial support. There has been no help from anyone except family.

The parents have brought up Devna and cared for her happily without any pressure or tension in the family. Everybody has played with her since she was small and the neighbors and village people enquire about her well being. In seven years nobody has said anything to hurt her feelings or made fun of her. They have a joint family with the Grandfather, Grandmother, Brother, and bhabhi. Devna, Shivansh (2 years 5 months old) and her cousin brother play together. Her cousin's brother is less than one year old. The neighbors' children also come to play with Devna. The parents have got a “Jahaaj ” for her “Ghumne ke liye” she sits in it and the children push it around the house to give her a ride. She moves around in the house in the “Jahaaj ” sitting in it. She plays with toys. Her favorite toy is “Gudiya ”. Shivansh is fond of playing with the phone, she said. She can read and eat food herself, and do her homework sitting. When she wants to go out she calls out “ Papa mere ko bahar jana hai”. She can color pictures. She gets up at 8: 00 AM, she

takes a bath on alternate days in the winter and everyday in summer she said. Her mother gives her a bath, she eats one "Roti " in the morning then she goes to school. The parents drop and pick her from school. When there is a "Bhandara " in the village or neighboring village she wants to go there to eat "Kadhi Chawal ". She is first there and in case her father is busy she goes with her "Baba ji". She has participated in every "Bhandara ". At home she has less rice but enjoys the food there. She does not have a sweet tooth. Her "Baba ji " is her friend, he spoils her for everything. Her every desire is met and the parents also get scolded if they do not give her what she wants. Initially she used to eat "samosas' ' a lot but now they have reduced the same. They have reduced their "Pizza" intake also but when the children insist she gets her "Pizza". When Devna gets angry she really creates a fuss, she refuses to eat food and tells them to go away. She gets angry when her parents tell her to eat one "Roti" instead of two at night. She has one "Roti" now because her father has told her to have milk instead. She does not have milk when she has a cold.

She loves both her Mother , father and Shivansh, she said. Today she insisted that her father accompany her to Swach for the interview and not mother or "Baba ji " as they do not know anything. Only her father will accompany her today. Shivansh is her friend and she talks with him maximum. She tells everything and shares everything with her father. She goes to the family shop in the evening after doing her homework and sleeping some days. She likes to go to Panchkula out of town for an outing, she likes the "Jhula " swing for play.