Deesa Mission

Sudeep's invitation to join the Arpan Global Team Mission to Deesa, India launched a huge opportunity for me to rediscover my birth place, reacquaint myself with relatives and friends and visit the family home after 30 years. The opportunity to learn about medicine and in particular clinical genetics in Deesa, where I was born in the State of Gujerat was difficult to turn down. The mission for me started with a potluck organized by Sudeep at his home where I met the majority of the 30 brave souls who planned to participate in the mission. Prior to that my only tasks were to purchase my ticket and arrange for my visa and immunizations to India.

Twenty of us travelled together on Emirates Airlines and arrived in Ahmedabad on a Saturday early morning at 3 AM where we met up with all the other members of our group, who planned arrivals on domestic airlines. A coach came to meet us with staff from the Gandhi Lincoln Hospital and drove us to Deesa, approximately 3 hours from Ahmedabad, with the roof atop with our luggage. We were greeted by Dr Jagdish Soni, superintendent of the hospital and were treated to a wonderful Gujerati breakfast, before settling in the rooms arranged by the hospital. A group chose to stay with me at my family home which was a 10 minute walk away, rather than the hotel located at the outskirts of the town. My family home which I only knew from photographs proved to be a very pleasant and safe haven, made all the more special because of my cousin Hyacinth and her daughter in law Nisha who kept a keen watchful eye for all our needs, made hot water for our Balti baths, and provided us with homemade Indian style omelet's for breakfast with endless cups of coffee and spicy Indian tea.

On our first excursion we were taken to the diamond cutting factory for women, run by the Bhansali Trust who also runs the hospital. The factory supports women who are widowed or whose husbands for some reason are unable to work. We got to interview the women, observe their detail oriented work involved in polishing tiny diamonds. The starting minimum wage is 1500 Rs per month (approximately $30/month, however the women can easily earn several times that based on their productivity.

The next day we had planned to visit Mount Abu a local beauty spot however because of the need for a permit for our bus to cross State lines we visited some beauty spots in Gujerat instead. This was a full day starting with a tour of the Rani ki Vav, which means the "Queen's Step Well" in Patan, and dating back to 1022 AD is one of the excavated remnants of the original palace.

Rani Ki Vav

Modhera Temple

Patola House Sari Factory

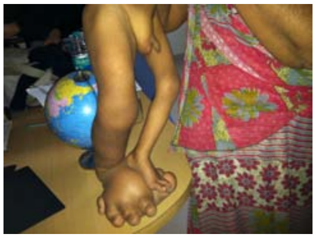
The carvings were exquisitely preserved primarily because the structure was buried until its discovery and excavation. Nearby was the Shastra Lin, a lake with columns in the middle which resembled the carved columns of a Grecian temple. Nearby was a sari making factory which continues sari making the traditional way by the same family through generations, who are justifiably proud of the medals and other accolades received for their fine skills. There is a long waiting list of orders for their sarees even at the handsome price charged of thousands of dollars. We next visited the Modhera temple with its adjacent lake with 108 statues. The carvings of the temple were beautiful and a feast for our eyes. Soon after sunset we arrived in Balaram, a lovely picnic spot in Palanpur, 30 minutes from Deesa and were treated to a wonderful meal at the exclusive Balaram Hotel frequented by Indian movie stars.

Our first official day started with a tour of the Gandhi Lincoln Hospital run by the Bhansali trust. In addition to running the hospital the Trust emphasizes health in rural tribal areas. One of our first stops was the alcohol and opium addiction unit where patients are treated for one week at a cost of 100 rupees ($2) per day for food, accommodation and medication. Patients sleep on the floor to avoid them falling out of bed during the detox process for alcohol and opium addiction. For the opium users they are given opium powder which is gradually substituted over the course of the week to powder. Opium is readily grown in many parts of India so controlling addiction presents a huge problem. We got to interview the group who were being discharged after their week long treatment. One man ages 45 said he spent $40 on drugs and $1 on food per day. The increased expense of the drugs was huge incentive to give up drugs however a significant number of individuals do relapse.

Continuing with our tour we saw a baby with tetanus who had been extubated after being on a ventilator for a month. He had developed gastric bleeding presumably from stress ulcers and was also seen by the orthopedic surgeon for restricted movements and an abnormal right hip. The NICU was only populated by one baby who was being treated with bilirubin lights. The NICU was being renovated hence the census was down. We visited the OR, ER, dialysis unit and other wards. One striking observation was the number of flies in the wards. The windows were at one time covered with netting to keep flies and mosquitoes, however the patients had a habit of tossing their food out of the windows through the netting making it a health hazard and the nets were removed. The challenge is to find a way of achieving a balance between these problems.

Clinics on Monday and Tuesday were together with other mission specialists and the local physicians. The surgeons planned surgeries after evaluating their patients in clinic. The medical teams also visited and participated in rural clinics run by the Bhansali trust in cooperation with government programs. The director of the rural clinic informed us that the vaccination program in their rural areas was a great success with an 85% immunization rate. One of the field trips included a visit to the Mah Shravan Vani School for the Hearing Impaired and Visually Handicapped and the Mamta Mandir Institute for Handicapped Persons. The children were beautifully looked after by a group of highly motivated staff. The art work produced by the children was stunning and I will always treasure the paintings of the children that were so generously given to me.

Before my visit I tried to find out about genetics in Deesa, only to discover that there is no testing or treatment available for patients with genetic disorders. The nearest center is run by Dr. Jayesh Sheth 30 miles away in Palanpur. I did however see several patients with birth defects the most dramatic of which was a boy with a large right leg and foot and a lymphangiomatous chest wall lesion from Proteus versus hemihyperplasia syndrome. Treatment for this patient was not within the scope of our team. Another patient included a girl with developmental regression, seizures, mental retardation, microcephaly in whom Rett syndrome could not be excluded. I obtained blood for MECP2 sequencing and deletion testing by a lab in the US gratis. Duchenne muscular dystrophy siblings the only children in a family had been told there was nothing that could be done and sent home. They were asked to return for dystrophin testing for in frame versus out of frame deletion testing which was available at the Genetics Centre at Ahmedabad at the reduced charge of 2,500 Rs (discounted from 4,500). Prenatal testing was discussed and the boys were started on prednisone and an echo and EKG was requested for the associated cardiomyopathy. We saw a patient with respiratory infection and failure to thrive whose two siblings, a male and female died from respiratory illnesses presumed to be cystic fibrosis or a recessive immune deficient disorder.



There were several other patients with unknown syndromes however investigative testing could not be offered because the family did not have the financial resources for the testing. Patients with undiagnosed disorders included children with undiagnosed mental retardation, speech delay, primary microcephaly, a child with meningomyelocele and rocker bottom feet, a child with hydrocephalus small cerebellum and crossed toes, and a girl with MR, cataracts, right hemiatrophy and flexion deformity of the right foot. I shared these cases with colleagues and Dr. Soni who agreed that the sample of patients I had seen were the tip of the iceberg, with a great number of patients with genetic diseases which were not recognized or treated.

Overall the mission was a great success. The patients and their families and hospital staff were so grateful and appreciative of our efforts. Some stellar examples of the contribution of our team were the types of surgeries performed such as the gastric pull-up and cervico esophagojujenostomy on a 40 year old male with corrosive esophageal strictures and pyloric stenosis resulting from ingestion of acid mistaken for water. The major challenges remained the limited resources available for patients, the lack of specialists with the skills to diagnose, treat and work with patients, the financial limitations of families leading to patients being deprived of life saving treatment and sometimes being taken home to die. Above all was the lack of testing and treatment options, which we in the US take so easily for granted. The hospital did not have a microbiologist on staff. Consequently patients were treated empirically with upto 3 different antibiotics to achieve broad based coverage rather than be guided by culture and sensitivities.

The smiling faces of the patients and staff will always remain firmly etched on our minds as we plan for our next trip back on a future mission.

Virginia Kimonis