Give and take in kidney chain

LAST MONTH, SURGEONS IN THREE MUMBAI HOSPITALS CONDUCTED INDIA'S FIRST DOMINO KIDNEY TRANSPLANT INVOLVING FIVE PATIENTS AND A DONOR FROM THE FAMILY OF EACH. MIHIKA BASU REPORTS

IVE kidneys, 10 persons, 40 doctors, 10 operation theatres, three hospitals and simultaneous surgeries lasting six hours. These statistics for India's first domino kidney transplant, conducted in Mumbai on June 25, tell only half the story. The other half involves the two years spent plan-ning it, and now, after it is over, the celebration of the gift of a new life in five homes, in Mumbai and an unspecified place in Rajasthan. It took 30 months to deploy this

domino, the idea having germinated even before the the Apex Swap Trans-plant Registry (ASTRA) was started in January 2011. Five doctors from Bombay Hospital, Hiranandani Hospital and Hinduja Hospital formed the core team and would refer their patients to the registry.

According to experts, there re-mains a significant patient pool waiting for a transplant in the absence of a matched family donor and because of long waiting periods for a cadaveric organ. A subset of these patients, who have donors in the family but with blood group incompatible, can potentially benefit from a swap transplant.

ASTRA's database manager periodically runs through the registry to identify potential donor-recipient pairs. "Once a pair is identified, a cross-match is done and, if negative, their two primary nephrologists are intimated, who organise a joint meeting with the pairs and undertake the documentation and legal sanction to per-form the transplant at their respective transplant centres," says Dr Ganesh Sanat, coordinator of ASTRA.

The only one of its kind in the country, ASTRA has facilitated 27 transplants in the last one-and-a-half years. It initially facilitated binary swaps; in two months from now, four patients will undergo a binary swap.

On June 23, two days before the surgeries, Umesh Dedhia, Samsunissa Mohammed and a father and daughter from Rajasthan checked into Bombay Hospital; Surekha Dedhia, Kashinath and Sushma Kochare, and Rajesh Purao into LH Hiranandani Hospital; Smita Purao and Arif Mohammed into Hinduja Hospital. On June 25, the surgeries began at 8.30 am. By 2.30 pm, five of them had new kidneys. According to the team of doctors, all are doing well.

ARIF MOHAMMED 36 I RECIPIENT SAMSUNISSA (WIFE)

34 | DONOR ARIF MOHAMMED lives in Ganesh Murti Nagar, a slum area in Mumbai's Colaba, past some narrow lanes and up a flight of steep steps. His one-room house is in contrast with the surroundings. As Arif sits on the bed, a surgical mask on his face, the room is kept dust-free.

A barber and father of three, Arif used to supplement his income by selling soaps, shampoos and similar items. In 2009, he came to know both his kidneys had failed.

"My mother was found to be a tch. But tests revealed her kidney was not strong enough for the transplant," he says. "Another attempt remained unsuccessful when I contracted TB before the operation.

In 2010, Arif began regular dialysis. Then, two months ago, he got the call. Arif was told he could be part of a 'swap transplant".

Arif agreed, and soon met the donor, Smita Purao. "I remember how for the first few minutes after we met, we didn't speak a word and just smiled at each other," he says. As part



"I was scared... Samsunissa and I were being operated upon in separate hospitals (but) everything kept falling into place"

of this swap, Arif's wife, 34-year-old Samsunissa, donated one of her kidneys, to the woman from Rajasthan.

Arif admits he was scared. "My wife and I were being operated upon simultaneously in two separate hospitals. I had to steel myself.'

The operation cost Rs 5.5 lakh, and the couple had help from several quarters. While Hinduja Hospital bore 50 per cent, the remaining came from trusts. "Everything just kept falling into place. Without the help we got, it would have been impossible for us to afford it," Arif says.

RAJESH PURAO SMITA PURAO (WIFE)

RAJESH HAD been admitted to a hospital because of severe pain. "He had high blood pressure too. Subsequently, we came to know both his kidneys had failed," says younger sister Rakhee Soni.

No match could be found in the family and they had to wait almost a year before they were offered the domino swap in April. Rajesh was hesitant but Smita saw it as a "blessing". "I thought why not? Giving a ey was a small price to pay for getting my husband's life back. He, however, didn't want the two of us to undergo such a major surgery at the same time, as we have a 12-year-

Sitting in their two-bedroom house, the Mira Road resident says it was the doctor who finally convinced Rajesh. "The doctor explained that there could be side-effects of dialysis and my husband wouldn't be able to

take it for long," says Smita. She donated a kidney to Asif,

while her husband got one from Kashinath Kochare. As the Purao fam

KASHINATH

with post-operation recovery and higher costs, help is coming in from relatives, parents and siblings. "We are managing. My husband is eager to get back to work as soon as possible," says Smita.

THE COMPLETE

WHO DONATED THEIR KIDNEYS

TO WHOM, AND THE HOSPITALS

THAT DID THE SURGERIES

RAJESH

SUSHMA

Yash is happy his father does not have to visit doctors frequently. "I was not scared that both my parents were going to be operated upon. I just wanted them to come back home as soon as possible," says the Class VII student.

SUSHMA KOCHARE ASHINATH KOCHARE (HUSBAND)

FATHER

SUREKHA

DAUGHTER

UMESH

SUSHMA'S FIRST kidney failed in 2010 and the second in 2012, owing to side-effects of medicines she had to take when she had malaria along with high blood pressure. "She had to undergo dialysis thrice a week and she could hardly move. It broke our hearts to see her undergo such suffering," says Kashinath.

Earlier this year, they registered

with ASTRA. By April, representatives from the registry informed the family that they had found a donor, Surekha Dedhia. In exchange, Kashinath would donate his kidney to Rajesh Purao. "I answered the phone. After I heard the news, I don't know what exactly happened, but there were tears in my eyes. I knew my wife's suffering would finally come to an end," Kashinath says

"I was never scared. I took a month's leave, but I may just go back to work earlier," he says.

"The total cost was over Rs 5 lakh and before that we had to spend a considerable amount on dialysis. Our finances are not that sound, but we

are very happy that everything went off smoothly," says Kashinath. Resting in her flat in Badlapur, Thane, Sushma says, "Trying to sit used to be a major task. Things have changed now."

The Kochares are in touch with both the donor and recipient families. "It's a journey and does not end with the surgeries. We try and give each other moral support. We've been through a similar experience," Kashinath says.

Their 15-year-old daughter, Harli, calls the domino swap a "revolutionary initiative" in medicine. "I have always wanted to become a doctor and this operation has inspired me even more," says the Class X student.

UMESH DEDHIA SUREKHA DEDHIA (WIFE)

37 | DONOR UMESH'S BUSINESS, a small general store supporting the family, came almost to a standstill for two years after he started falling sick. Surekha didn't have to think twice when the offer for the domino swap came in. Umesh got a kidney from a donor in Rajasthan, while Surekha donated one to Sushma Kochare.

"It's a relief that the operation went off smoothly and he is back home. We are now taking all steps to make sure that he has a speedy recovery," Surekha says as she puts on a surgical mask before handing over the medicines to her husband at their Dongri home.

Ria, 17, Surekha's daughter and the eldest of their children, juggles between studies and taking care of the home. "It's just a matter of managing your time wisely," says the Class X student.

Umesh's younger sister and niece have come down from Satara to take care of him and Surekha, who too is recuperating after the operation. Umesh calls the operation nothing short of a miracle. "It is the future of medicine," he says.

FATHER DAUGHTER 34 | RECIPIENT

THE TWO of Rajasthan have requested the doctors that their identity be kept a secret. The father donated a kidney to Umesh Dedhia; the daughter received one from Samsunissa.

Dr Viswanath Billa, consultant nephrologist and kidney transplant physician at Bombay Hospital, says the two were suitable for a binary swap with Samsunissa and Arif but agreed to be part of the domino chain as it could save more lives

MAKING A BEGINNING

DOMINO KIDNEY transplants are a routine procedure in North America and Europe. India's first took two years in its execution.

A first attempt failed when a patient from Maharashtra, around 45 years old, died while still waiting for mandatory approval for the first domino operation from Maharashtra and Andhra Pradesh governments to come through. The tragic death, however, helped sensitise the authorities.

"The hurdles were not at the pats' end. They were more than happy to participate," says Dr Viswanath Billa, consultant nephrologist and kidney transplant physician at Bombay Hospital and coordinator of ASTRA. "The challenges were in educating the statutory authorities on the feasibility, legality and benefit of such a mechanism. This is of high utility in a country like India, where the cadaver transplant programme is still sub-optimally developed. This method opens a window for a subset of patients with organ failure who, despite having a donor within the family, are incapable of undergoing a transplant because of blood group incompatibility. This will prove beneficial to about 20 per cent of patients undergoing dialysis in India.

Dr Billa stresses the benefits of ASTRA: "As the database becomes larger, it will be possible to apply other types of mathematical models and algorithms that can benefit patients with rarer and more difficult blood groups. It took 30 months to deploy this domino.

Dr Jatin Kothari, consultant nephrologist and transplant physician at Hinduja Hospital, says that of the 2,000-odd patients waiting for cadaveric organ transplants in Maharashtra, even if 20 per cent get a match through such domino transplants, it will help fill a huge void. "The next step is to create a link between the cadaver and swap programme and make them work simultaneously, so that hundreds of patients can benefit," says Dr Kothari.

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pay for getting the life of my husband (Rajesh) back"

SMITA PURAO