

## **Rare Lives : The Impact Of COVID-19 & Lockdown On People With Rare Diseases**

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**Avantika Shrivastava (Host):** The Coronavirus pandemic has caused much uncertainty in all our lives, has it not? Now think of people who are facing chronic medical illnesses, which not many people who have understand. Hi! I am Avantika Srivatsava, host of this podcast series on rare diseases. In season 1, called 1 in 20,000, I took you through the challenges facing rare patients and their families.

Rare diseases are complex. This is why I and Suno India are bringing out Rare Lives which is the [second season of 1 in 20,000](#).

As per an estimate, it takes almost 7 years for a patient in the American healthcare system to be diagnosed with a rare illness. Even then, chances of misdiagnosis run high. But India has no such estimate because it does not have an exact number of people with rare diseases.

In India, policymakers are faced with the unenviable task of prioritising some lives over others. This is because the number of rare disease patients is always less compared to those at risk from, say, malnutrition or more-known illnesses such as diabetes or blood pressure.

COVID-19 has added complications and challenges. But this new season is not to count challenges. Rare Lives is to give you hope in dark times. Its message is simple - each one of us can do a lot for people who are more vulnerable to the infection from where we are, including those who are rare disease patients. The first step is to raise awareness about them and their needs.

For the first episode of Rare Lives, I spoke to Dr. Deepanjana Dutta, a genetic counsellor based in Kolkata. She had also featured in the last season. I reached out to her again to know how the Coronavirus pandemic was impacting rare individuals. This is what she had to say during our discussion.

**Dr Deepanjana Dutta:** *In the initial periods of [the] lockdown, we didn't know how long it will be so parents were just waiting that- let this one week end, let this [sic] 20 days end, we will resume*

*the therapies. That has harmed people a lot like, you know, because it has put pressure on the people in a huge way.*

*There was a kid who was in the suburbs and that kid was having, you know, huge issue with eye and the clinician there was treating the child with antibiotics. But antibiotics was [sic] not working. The child needed an MRI, the MRI had to be happening in this side [of the city], not there [suburbs]. In fact, what happened was that the child was being treated for infectious disease, and we were passed on the pictures of the child, one of the clinicians saw the pictures and they felt that this was not an infection. This was in fact a tumor!*

**Host:** When Deepanjana received the call, she knew she had to act fast.

**Dr. Deepanjana Dutta:** *And he immediately asked them to come over to Tata Medical College over here and get that evaluated and also start the therapy following MRI but, at the same time, they were unable to even come so they just texted that it is a problematic situation for them to come over here. So we got involved and in this place what happened was that we connected to the local thana [Police Station] over there because at that time, they were giving those particular permits to come. But these people were so poor, but the OC [Officer-in-Charge] of that particular thaana was so good that he said that 'I'll give my own car', you know, 'my own transport I have and they will carry until the child reaches the Tata medical hospital and will ensure that the child has the primary care that is needed'.*

*So, see a lot of people got involved in this one particular case. But again, not all cases are able to find the right sources or not all cases were able to find the reach out.*

**Host:** If you followed 1 in 20,000, the startling figure of an estimated 70-96 million will not be new to you. That's the number of people living with rare diseases in the country. Since India does not have an official definition of what a rare disease is, the number of people who actually have rare diseases is not known. It is therefore possible that the figure is more than 90 million Indians of which the boy Deepanjana talks about is one.

**Dr. Deepanjana Dutta:** *If they [government] would have thought about the rare disease patients, and if there was even a bit of thought, then a cell should have been set up where the patients with rare diseases and the families could have had their queries directed. Like in each state, there is already a rare disease Task Force present. These Task Forces were not used at all.*

*There are NGOs present, and there are different patient support groups present. But the issue is that not everybody knows this [information on Task Forces or remedy]. If I know a patient support*

*group, I can go and call up and direct. But if I don't even know that something like this exists, then it is very difficult for a person who is from a rural, or urban area or even a city. If that connection is not made, then the person would find himself or herself lost!*

*So the whole point was probably not, putting everything on the government, but also having few people who would have thought about these rare [sic].*

*Even now, which is a huge concern for the rare disease families, is that what happens when one parent gets affected? There are many parents right now who have to step out and they might get infected, in that case with no maids, nothing, and they are trying to sort of live, and these children are also susceptible. What happens to the child? Who is the primary caregiver of the child, how will the child isolate, how will that work out? Nothing is there, there is no policy to work.*

*The clinics that were open were very costly for them to even go do the dialysis, and there was [sic] also the COVID restrictions, which right now to a certain extent, is getting ironed out. But in those moments where the lockdown was so sudden, these was [sic] so unplanned, [it was] at that moment that many people had a problem.*

**Host:** To understand why the chances of doctors misdiagnosing rare patients are high, I reached out to Dr. Apurba Ghosh. He has been a pediatrician with an interest in rare diseases for more than 40 years, and is the director of the Institute of Child Health in West Bengal. With his extensive experience, he explained to me what's exactly taking place.

**Dr. Apurba Ghosh:** *My interest in rare disease grew when I went to England. Before that, my colleagues and seniors used to say that they never diagnosed a rare disease and were never correct. They used to used to say that 'what can you do about these rare diseases, you cannot treat?'. Now, after going to a developed country, I have seen how much care they take about these rare or uncommon diseases. Because to us, this may be a rare disease, but to the parents that is not rare at all. Because that has happened in their home, to their children, to their child. So, they want an answer, 'but what has happened to me, my child?'. The next question will be 'can you do something about this child?'. And third question will be that- 'how can I prevent [a rare disease] in the next pregnancy?'*

*So, I must say that the rare diseases are not really rare, correct, collectively, they are quite common. And in some cases, it may be in the tune of 3,000 to 5,000 if you collect all the rare diseases together.*

**Host:** So my next question is actually on what we were discussing. And that is- it's the fact that a lot of doctors in India don't know a lot of rare medical conditions, let alone being able to diagnose that. What has been your experience? And what are you going to say to the medical fraternity on diagnosing and knowing and increasing awareness about rare medical conditions?

**Dr Apurba Ghosh:** *Okay, let me go to the basic problem first. In our undergraduation, we didn't have paediatrics as a separate subject. Okay? So, it was only a part of general medicine. And we used to read about a lot of diabetes, hypertension, all these diseases, so your undergraduate training of [sic] paediatrics is very poor! I will still say it is poor, but it has improved after the paediatrics was included as a subject.*

*Now, if the paediatrics is included just as a subject there, the metabolic diseases, rare diseases, genetic diseases are not really covered very well. One of the main reasons for that is [because] the teachers themselves are not very well versed with the rare and theoretical cases because in most of the paediatric departments of the Medical Colleges, you don't have a teacher of genetics. It will take another maybe 15-20 years to have a teacher in either undergraduate or postgraduate trained in genetics or metabolic diseases in all the medical colleges or all the postgraduate centres. Unless and until your teacher knows, genetics cannot be your bread and butter in this part of the country.*

*Now, because the orientation [of] the doctors is not there. So, I'm trying to train one or two who will be interested, we will be able to do that test and we will be able to do the counselling and then take help from preceptors like Delhi or PGI Chandigarh, AIIMS, Vellore or one of two centres in Hyderabad. My single answer will be that try to include the genetics from the first year to final year!*

**Host:** *Thank you for listening to this episode of Rare Lives. If you haven't listened to season 1, no better time than now to catch up on the episodes now. Don't forget to subscribe to this podcast on Apple iTunes, Google Podcasts, Jio Saavn and any other podcasting app of your choice.*

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