A Father's Journey

A- Avantika (Interviewer) J- Mr. Iftekar Zia(Interviewee)

Welcome to our brand new episode of 1 in 20000.
Last month we spoke about inter-abled couples and got the perspective of Ms. Sangita Goyal whose husband has a rare medical condition. This month we are going to continue exploring her family's change and cope with the rare diagnosis. Mr. Iftekar Zia is parent to a well-educated and able son who has a rare medical condition. Mr. Zia is now a patient advocated ORDI and shares his journey as a father.

A - Welcome onboard it is just so great to have a chat with you considering the kind of work that you are doing and also how you raised your son and the first question that I would most definitely ask you is your son is a highly educated, independent person now but when was he diagnosed, what was he diagnosed with and what were those initial months like for you as a parent. Could you shed some light on that?

J- What my son has is termed as Ataxia and currently it still remains as an undiagnosed one because all the available tests he has gone through and nothing concrete on the numbering as far as the Ataxia numbers are concerned have been confirmed for him so as such it is considered as an undiagnosed case of an Ataxia. Ataxia affects the gate movement mainly, there is a poor coordination of the limbs and then as it progresses it affects the speech and eye movements also and each Ataxia has a different progression rate and what it affects. It is like any other rare disease, it is a rare disorder, there is not a specific classification for which why a patient, a person can go saying that this is how it would affect him. This was a late onset for him. It was not by birth and in fact I had suspected there was something wrong with him for some time, maybe a year or so before the diagnosis took place. I kept asking him if there was something physically wrong with him. Everytime he stumbled, everytime he dropped things, everytime he fell down. In situations where normal kids don't you know and every time he said no, everything is alright he use to say. In my heart I wanted to believe what he was saying but I knew there was something wrong. When things were becoming very apparent, I guess it was around 2010, when he was in his 11th standard that is when we got his brain MRI done and which showed that there was a diffuse cerebral atrophy. There was no known cause, there is nothing in the family and it was not even heard of the name kind of Ataxia when we were told that he has Ataxia it was a new name for us with no medical understanding also. That particular stage was a very difficult time for us. One was being informed about the rare disorder, two was the continuous running around which took place involved between hospitals, doctors and diagnostic labs and third the most important concern at that moment for us was that he was going to his 12th standard which was an important landmark period for any student's life. So initially I would say it was quiet a year which was a struggle for us because for me and for him it was we did not know whether to pursue the medical things at that point or whether to give up that and concentrate on his education. You know it was a real turmoil for us. But somehow you know it was i would say a

joint effort, there was support from the school side, there was drive from my son himself to overcome this particular situation and I was as a parent getting more and more concerned about him clearing his 12th standard. You know that was usual as a parent thing, that was a concern for me. So that was a real turmoil period, one year I would say was a real tough time for us to get things organised and keep moving ahead without getting moved away from our focus.

A- So it was a life altering event not just for your son but also for your family. Could you let us know a bit about who else is there in the family, the immediate family?

J- See I have a daughter and my son is there the elder one. I have a son and a daughter so my daughter she is doing Architecture. She is studying Architecture, so it is a family of four of us and we have a joint family kind of stuff, we have an extended family which is quite big and supportive as such but then you know the first impact would always be the mother and father you know. What happened was it was a life turning thing for Zoaib as well as for me because I had to make a choice with either going ahead with supporting him or going ahead by taking care of my own livelihood. So it was a very tough call which I had to take when I had to give up my job. A year I continued trying to juggle the job as well as taking care of his education and taking care of his medical needs but then I had to take a call at one point. It was either me or him so I opted to step out of my career and devote more time to his education and his career growth and I guess it was a good decision I took because he performed after that and I also had a feeling that I did the right move at that moment because if I had progressed on my career then I might have had to let him down.

A- That is a very tough decision to take and I would want to know more about the dynamics within the family. Sometimes when a sibling has a particular medical condition, and in this case it was a delayed onset in the sense that the condition was not necessarily by birth, the symptoms started much later. So the sibling sometimes would feel that the parents are paying a lot of attention to one sibling. That's not always the case but it could be the case. So what was your experience like?

J- See actually what happened was, my son was at that particular moment was trying to backout or rather shut himself off from everything, it was a difficult stage for him also. Basically it is a teenage period when he would realise that things are not going the way they are supposed to be going and then he moved away from all his friends and he kind of backed out from the family. In the sense there was a little bit of gap which came in between him and his mom and his sister also. So it was a short period I would say because that was the time when he was not coming to terms with the situation what has popped up for him. But luckily for me I did not find that sibling rivalry or that difference being felt because it was an immediate acceptance by the family that he needs the support. It was on the other hand I would say like people trying to actually coming forward to help him and he was trying to move away from that scenario.

Probably he felt that people are having kind of sympathy on him which was not exactly the case. It was more of a concern rather than sympathy so that yes it did crop up but not the

way you say that there was some sibling finding that I am giving attention to one person and all that. It was a joint effort I would say because my wife also like how I went around silently

without discussing with anybody or without trying to disturb anybody, she was going silent in a different way and trying to understand what was going wrong with this guy. It took sometime for us to again regroup and again come back, it was you know luckily I would say that Zoaib was very fun loving kind of a fellow, humorous and funny kind of a guy who is always happy and jovial and making fun and all that kind of stuff. So suddenly you see a guy who is playful like this, he was quite an active guy, he was a swimmer , he used to play football and he used to do gymnastics and apart from all this other tricks and all that. He was a very active guy and very jovial kind of a fellow. When you see a guy like this suddenly going into a shell it is difficult for others to understand what is wrong. So that kind of thing we had within the family but luckily everything worked out well. Now we are again back to pulling each other's leg and having fun with each other and things go around like everything is normal kind of stuff.

A- I think Zoaib had to grow up much faster than other people as well.

J- Every situation I would say, every challenge not just a rare disease, any challenging situation is normally faced or handled by people in different manners. You know there is no set rules saying that at this age things could have been handled and at that age things could have been handled. We have seen smaller children who have become achievers and performers and mature guys just crumbling down with just one slightest down fall. So I think it differs from person to person. I would not say it is because of a rare disease or something that things change.

A- Have things changed? The things you're talking about changed?

J- Things have changed a lot, I would say a lot since with the time it started you know. Actually that was a period of I would say confused teen phase he was going through before the diagnosis plus you know he was trying to hide his physical issues which had actually made him a mess. He did not have many friends, he would not talk to anyone properly, he had a bad mood constantly, he would get angry quite easily and quite often and all the constant medical rounds and the negativity surrounding the disorder and the fact that there are no cures, these had an impact on not just his mind, I would say mine too. On the back of our minds you know sometimes giving up was an option which used to keep popping up in our mind and I guess anxiety, tension and depression are all a part of Ataxia itself I guess. It may be the case for other rare disorders too or maybe all other health issues I would say. These tensions and anxiety and depression I think it could be found in other people but more so with something which is related with the brain neuro disorder, I think this is a common problem I guess. So one can sometimes see a huge swing in the moods it is just from zero to hundred kind of mood swings are there sometimes. But now things are different. He is more calm and composed. He thinks straight most of the time. He has become more focused kind of knows what is workable and what is not for him. He is clear on his career, education and goals. And he has a lot of positive ideas too. He has gotten close to family and friends even lets his sense of humor show sometimes. He goes out often with his friends and cousins now. His journey so far from school to college to now teaching profession has not been easy I would say. It has

been a difficult one. He has been helped by a few, let down by a few, ignored by a few that has been the journey so far. Now he plans to start his Phd. and his exploring topics options

and mentors at the moment. There are a lot of differences, it is totally a different guy what he was about 8 to 10 years back and today.

A- Life doesn't stop just because you have a rare condition. That's what I am getting from what you are saying.

J- Exactly, exactly.

A- Right, so I would want to go a bit deeper into your experiences as a parent. How have you grown as a parent of a child who is able bodied and then also parent of a child who is different from the norm, who has a rare condition.

J- Yeah, see in fact I would say just not a father a son equation, it converted into a kind of a partnership between us. We started understanding the strengths and weaknesses of each other, a kind of a you know we started respecting each other's weaknesses because he was also understanding that there are certain things happening to my personal life because of his issue that had popped up and that was one of the things which was sometimes keeping him a little slowed down because he was sometimes popping up the question that you know my life is getting spoiled because of his conditions. But you know our journeys so far, both me and him we have learnt quite a few lessons in fact my son wants to start motivating others especially the students. It really is not easy but sometimes determination can make you perform far better than your imagination. When one is faced with so many difficult situations it is not easy to stay focused and keep moving ahead but then you are left with no or little choices. Ignore or conquer the worries and keep moving ahead. Stories from families of a person with rare disorder are nearly the same I would say. Probably the name would be different, the location, time, the hero or heroine and the villains in the story might be different but the theme would remain the same. Parents have lost their jobs, their businesses, their earnings, all their energies have been drained, they would have probably disassociated themselves from the society also. I come across a lot of families who go through this particular situation where they are not even if they want to accept what is going on, they are helpless, they can't do anything, they can't go ahead you know just accepting is not solving the issue kind of stuff. And at over the organisation for rare disease in India, we meet some amazing people. It is either the persons with rare disorder or their parents who are determined to create an awareness, help in connecting people, and basically you know working on finding solutions for the entire community. As a parent individually if you personally ask me there would be a lot of stories, or lot of situations what I have gone through, I had to give up my job, I had to manage with some part time jobs but then we had no other choice at that moment so you take a call. That's it and that's what I would say to the parents also that you take a call, you take a positive move ahead and keep moving ahead. My message to all the parents also would be don't give up at all, just keep moving, just be in the mainstream, network and explore. There is always something or someone out there for you. You can make

your mark and cave a path for yourself. If not this, something else is going to workout that is what I have gone ahead with that idea.

A- That's a brilliant way to live. Indeed one must not stop and keep going forth that is definitely a motto that is going to inspire a lot many people who are going to listen to this podcast. I would want to bring in one aspect of this. You are already working with parents of people with rare conditions at ORDI, I believe you are the state coordinator so you look at the macro picture but you also know the micro experiences. The day to day experiences of people. What I wanted to know from you is there is no solution because most rare conditions are incurable.

J- Exactly.

A- It breaks down family, it breaks down lives, it breaks down relationships, that could happen, that could most definitely happen given the adversity of the circumstances.

J- True, true.

A- You spoke of solutions, now what are the solutions where you are hinting at because right now well we cleared that there is not going to be a cure. One can think of it this was that you put on a bare face and you move on. But are there any other solutions that you are particularly referring to?

J- See, at the moment I would not say that there are any ready made solutions for anybody, for any rare disorder because some of the rare diseases or disorders, they do have a medicine kind of a stuff but it is not reachable. There are some branches of rare diseases for which medicine is available but it is not affordable. It is as good as saying you know it is making things more difficult for a person saying that there is a cure available but it is not affordable by me. So at ORDI what the organisation is doing is it is trying to build a support system at least to keep people living with a hope that things are working, people are working towards a solution. People are understanding. Until recently I would say people were not even aware of a rare disease. They did not know that there was something called a rare disease. And with the given means and the given terms and terminologies that are coming up I think it is just in the recent years that the doctors and the labs are now getting involved and trying to find out solutions. So what happens is when you have one case of like for example like Ataxia, there would hardly be a 100 people all over India. Numbers might be more but since there is a lack of registry, there is a lack of connectivity we are not able to find out how many else are connected. Same goes with all the other disorders. There are about 7000 and the numbers are increasing day by day as far as the rare diseases are concerned and each name is something, it is not even pronounceable kind of names which are being read out. So what happens is you know a person when he is affected with a rare disorder, the first thing he would like to find out is who else is there with this particular situation because they can understand what exactly it is because if he tells me what he is going through I really won't understand because suddenly he is saying that he is having this problem. I don't know that it is a digestion problem, or it is a headache or what it is. But then probably a guy with a same disorder would say that yes this happens. So we are trying to network. One is we are trying

to create a registry, and second is you know most of the places what we have seen is the people coming, they get diagnosed with one particular issue and then they just disappear from the radar. They do not come back to the hospital to check because they know it is going to be a situation where they want to be going up and down. Most of the parents, I would blame the parents as such, they do pursue for sometime but at one point they are forced to give up because you know support system is not there, there is nobody explaining to them what exactly it is. At ORDI, as a 23:45 organisation, an all India organisation we are trying to connect people with different groups, support systems at the moment we are trying to build up that and parallely you know the organisation is trying to work out with the Government for a better rare disease policy and insurance policy because these are things which are giving hope to others that there is something working on. Probably the person also would feel involved in it otherwise he is just you know cast aside saying that there is nothing for you because you know we have gone through this. I have spoken to a lot of people where people have gone through this, they have gone to ten different hospitals, people who could actually afford, have gone to ten hospitals, they have gone to all over India they have gone around, they have gone for alternative medicines and everywhere they get an answer that there is no cure for this, it could be progressive, it could get worse. There is no positivity coming out from anywhere, how long do you expect a person to keep going ahead, how long do you expect a person to be motivated and fully charged. At one point the energy levels have to get drained right? These organisation's work is one is to keep this thing upbeat, give them hope, tell them that yes we are working on it, we are looking into it.

A- Indeed it speaks a lot about our public system as well and how the public system needs to change, how our concepts about disability about rare conditions because not many people know about it.

J- Exactly they don't know, they just term them as a challenged person that is it. I would not say that it is wrong but it is slightly different from a regular challenged thing and this one thing because what most of these rare disorders people live with is it is a progressive situation. So what is today may get worse tomorrow. if something is not done to them immediately and some help is not given to them. At the moment they don't need sympathy that is what I have seen, they just don't need sympathy, they need support. There is nothing wrong in reaching out and supporting somebody if you can. If your are bold enough to reach out and hold somebody's hand for a couple of days. Probably you are holding the hand of a future engineer, a doctor or a lawyer. You name it, those guys have that stuff in they just need that guidance for the time being till they can come to understanding or whatever the situation is prevailing at the moment.

A- In the ideal scenario and situation indeed one would want a public system which works well for people with rare conditions and here I am differentiating people with disabilities because it is not necessarily somebody with a disability also has a rare condition. People with rare condition as you also mentioned have a very different needs. And it is part of their identity but not their entire life being which is something that needs to be communicated and needs to be, the dialogue needs to be opened on this.

J- Actually there was a rare disease policy that was formulated and that gave a lot of hope to many people I would say. There was a thing formulated and it was also conveyed and working committees were formed and people started collecting and you know once when you find that there is some help coming and there is some work going on on the other side then the people actually start working on it so this is what happened, lots of hospitals and lots of doctors they started working on it and started collecting information on some of the rare diseases for which some medicines were available at exorbitant cost which I told you. Somehow you know the policy was put on hold and it was kind of a let down for the people who were anticipating the medicines to come and I hope looking forward for this now that the Government has again formed I just hope that these guys again review these policies and bring it into force immediately. That would do a lot of help to these communities. At least for disorders and diseases where there are some medicines available and where there can be some food supplements given, some diseases and disorders they require a food supplement which has to be given to them lifelong.

A- So what is then needed is a public movement as such and which is what ORDI is trying to build in its own capacity. I would just want to mention here that we in Episode 2 we spoke with the Co-founders of ORDI, Mr. Prasanna Shirol and our listeners can access that podcast again. My next question would be on the extended family because you told me that while your son was diagnosed he got support from not just the immediate family which is the mother and the father and siblings but also the extended family. How do you see the role of the extended family playing in a situation like this. Many families in India still live in a joint setting that might not be true in big cities where we have nuclear families but somehow aunts and uncles and cousins can play a big role in bringing up a child with a rare condition so could you let us know a bit about that.

J- Yeah, it is not an extended family. I am not talking about someone living in a nuclear or a joint family, I am not mentioning about that because that actually does not really matter whether you live in a joint family or a nuclear family. The immediate uncles and aunts and cousins and all that they do play a very supportive role in almost everything. Let it be education, let it be growth so people who are well connected with their immediate extended family you will always find them to be happy and joyful and there is always a get togethers happening and something, some activity going on but nuclear family when you talk about people, I am not just talking about husband and wife and children there are kind of people who are kind of excluded from the circle itself that is a different scenario. Now if everything is going well and if it is going everything is fine it is alright. But when you do have a situation like this then I think there is a need not just for the family, I would say the neighbors, the society everybody has to kind of extend a kind of a small support. And support I am not talking about any kind of a financial support or anything like that it is just that a smile could do a lot of things to them you know. They being invited for every function and you know that that person in that house even if he is invited he can not come so he got to make arrangements for somebody to go and pick him up and come these are the kind of background work and supports which really make a person start feeling accepted.

A- It would be really great to know some of the joyous moments and triumphs that you have seen in your life and with your children as a parent.

J- That's what see as it is for me if you ask me Zoaib's performance right from a total standstill in his 12th standard to have come to a situation where he is talking about wanting to do his Phd in Genetics or Bioinformatics and then discussing some topics in which he wants to pursue itself is an amazing thing for me. A guy who was wanting to give up his schooling in 12th standard, he just sat down saying that I am not going to school this is it for me, I am going to drop out form that point coming to this level and then thinking in terms of what topics to do for his Doctorate by itself is an achievement. He talks in places for motivation and some of the people in fact take him to schools and ask him to give a speech on motivating people and in one of the inclusive summits he was a speaker and host for the occasion. So these are his achievements. These are personal achievements for him. He does face his problems but then everybody I guess in this particular situation, the situation on hand and how you overcame it is what the end result would be you will have to count. So these things have kept us stepped up for me to think that you know I would have sat down and worked on his you know I am working on who his mentors are going to be and which institute he wants to go for his Phd. He knows what he is, he knows he has got a progressive problem, he is working as a professor I told you, he is working as an assistant professor of zoology, he has completed his BSc, MSc and M. Phil in Zoology. He has done his BSc Psychology and he works as an assistant professor in a college. For two years he has been working as a professor but then as things are slightly progressing for him he is also wanting to get more into his research areas and like I told you know we don't have any differentiation. We do attend all functions, everywhere he is there, he goes to his football matches, he goes to the stadium to the football matches with his friends, he goes for his movies, all that he enjoys so I think these are all a little bit of joyous things for us to see that yes in given situation what we are going through he still is trying to manage to have a happy and joyful life.

A- That is such a heart-warming note to end this conversation with. Thank you so much for agreeing to talk to us.

J- I just hope that this message reaches to others also because I am very very particular that anybody who is having a situation on hand I feel that they can come out of it and at least make an attempt because you never know where you are going to succeed. Everybody is packed with so much of positive things in their own capacity and I just hope that the parents or the supporters or the well wishers tap those particular things and awaken those things for these fellows because these guys are performers Avantika, I have met these people and I have been amazed to see the work these guys do. Just amazed and I just pray that god keeps all these guys happy and cheerful and make them all achievers.