Alan Premasiri

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Samarth Dunakhe and Aryav Das of ALS Forward interviewed Alan Premasiri in September 2026. The video is at alsforward.com/interviews.

SAMARTH DUNAKHE 0:00

All right, so thanks for agreeing to join the interview. Can you introduce yourself, please?

ALAN PREMASIRI 0:10

Yeah. My name is Alan Premasiri. I'm the Director of Clinical Research Operations at the ALS Therapy Development Institute. Me and my team manage a natural history study that involves collecting data directly from people living with ALS so that we can use it in various ways in research.

SAMARTH DUNAKHE 0:29

That's really cool, thanks. So like going into ALS research, what like initially drew you to it? Like what's kept you going in that field specifically?

ALAN PREMASIRI 0:39

Yeah, it's a little sort of a long story. In college, at the end of my freshman year, I decided I wanted to be a neurobiology major. I was just very interested in any research that had to do with the brain and the nervous system. I had remembered that there was this group that came and visited my AP Bio class in high school. It was the company that I'm working at now to talk about ALS and introduce us to ALS. At the time, I didn't really care for it. I hadn't decided what I wanted to do with my career. It was interesting, but you know, I was sort of undecided. But then in college, when I picked my major, more specifically, I was like, Oh, yeah, there was that place that research lab that did neurodegenerative research, like that might be an interesting place to start. And I was pre-med too at the time. So it seemed like a good fit. So I reached out, that's how I got into it. And fortunately, they let me intern for a couple of years. And then why I stayed, really, there's a lot of reasons. The science is still extremely interesting to me, as devastating as the disease that ALS is. There's a lot of unanswered questions. The biology is very complex. And my motivation to try to help address those needs is still there, as just somebody who likes doing science. But then it's also just the relationships I've built since I started. So I've been with the company for

13 years. The people I work with are extremely smart and kind people, many of whom have been affected by ALS. And I've met a lot of people with ALS at this point, and I've built those friendships. And so there's the relationships and the wanting to help the people, you know, that I'm making friends with, the people that I've lost and the people that everybody else is fighting for. So it's sort of a two-pronged reason. yeah

ARYAV DAS 2:51

So that's great. I guess, to kind of go off of that, for the second question, I'm just curious since you've been working in the field, like you said, for 13 years, when you look at the kind of, I guess, ALS research today compared with when you kind of entered the field, what has, like, what do you say has changed the most? And what has been, I guess, the most impactful thing that you've kind of seen as, like, overcoming? Or maybe something that's like a new technology that you're really excited for?

ALAN PREMASIRI 3:23

Yeah, that's a good question. There's a lot of things that have changed in the last 13 years. And I feel like it's been exponential. So even maybe from 2000 to 2013, when I joined, it was, the amount of progress that happened there was nothing like the progress that happened in the last 13 years. But from when I started, there were, I think there was less understanding still about how genetic factors play a role in ALS. You know, we had some mutations that we keyed in on, but we weren't really developing treatments or there was one in the works for a really long time that finally got approved recently. And that has been the scaffold for new technologies, new genetic therapies to be developed. So like, gene therapies is one avenue. I think understanding just the disease and how it progresses still, we had a lot to learn. Collecting data from people living with ALS really only happened in drug trials, which are usually the data was held by the companies that run the drug trials and it wouldn't go back to the ALS research community to learn from necessarily. And so a lot of natural history studies, like the one we run, have popped up over those years, which has contributed to learning just more about how ALS progresses, which fuels everything else. All the drug discovery, all the understanding of biology is fueled by just learning from people living with ALS. And then, the technology itself has gotten more accessible. I don't know if it was the case when I started necessarily, but doing genome sequencing was very costly 15 to 20 years ago. And it was long and hard. And now it's a lot more accessible for organizations to access that as a research organization. And the cost has gone down Just because the technology has improved so much, the turnaround time has gotten shorter. And that applies to so many technologies in science. Sort of running assays and experiments have gotten cheaper and faster and more sensitive. We have AI now. So workflows that would have taken months to develop and test with very specific expertise can be started at least with AI assistance. So you cut off time that way. So I think it has led to this sort of like exponential growth in ALS research. All these factors combined over the last five years or so.

ARYAV DAS 6:26

Okay. Yeah. So to kind of go based off of that question, this actually really leads really well into my next question, which was basically like, you know, ALS TDI, I mean, this is why we originally reached out to you was because of like how open you guys are with data. And I guess you kind of mentioned it in your previous

response where you were like, people, you know, previously, there hadn't been as much data sharing. So to go off of that, like, why do you think data sharing and collaboration across like, you know, your institute and other maybe even for-profit institutes is especially important in like ALS?

ALAN PREMASIRI 6:58

So ALS is a very complex disease, biologically, and we still don't understand a lot about it. There are some hallmarks that are present in most of the cases, and we understand that some genes cause ALS, but the genetic component only appears in, or at least the inherited genetic, like the family history of it only appears in about 10% of cases, right? So in most cases, we still don't really know why it starts. And once it does start, we don't know what pathways cause certain symptoms. So everybody's symptoms can still be different, even if it theoretically starts at the same biological point. So some people might progress really fast in their upper limbs first, and then their lower limbs, and then they are not able to speak later, and sometimes it's the reverse. Some people are very fast, you know, they lose a lot of function within months. Some people can go a few years before they start to lose a lot of function. And we just don't know what is causing all of that. And because the disease is so devastating and so quick, in a lot of cases, we have to work fast. We have to make sure we're making the most of these people's time who are giving data to these studies so that we can learn. And by keeping the data separate or not informing each other of each other's findings, not informing each other of sort of what worked and what didn't work in certain protocols, it's just going to slow things down, right? So collaboration is key to making the most of the time and making sure we're moving as fast as we can. And really just making sure we're learning as much as we can. ALS is also kind of a rare disease. And so we don't just have thousands and thousands of people to get data from, right? And so we really have to make the most of the time that we have with these people and make sure everybody else gets to benefit from that time, too, right? And not just one group.

SAMARTH DUNAKHE 9:19

So what do you think, like, moving away from research more than, like, community perception? What do you think is, like, something about ALS that the general public doesn't understand, doesn't hear enough about, or is, like, misunderstood?

ALAN PREMASIRI 9:32

I think for a while, people probably didn't understand, and that was the case with me too, how devastating the disease is. So I think I thought of Stephen Hawking before I knew about ALS, right. And this, and he lived for decades. Right. And, and as far as I knew, like, he was like in, in his fully paralyzed state for, for so long, like, and that seemed fine. All right. Like, and that seemed fine, or like that seemed manageable to me, right? But people don't see the like, the decline, the people losing each function, you know, day by day or week by week, to get to the point where they are fully paralyzed, they can't talk, they have trouble breathing, right? And the effect that it has on, you know, all of their loved ones and the people who are taking care of them. It's just so quick and so devastating. I don't think it makes it into the public eye as easily because it kind of comes and goes like a monster. That's probably what comes to mind, yeah.

SAMARTH DUNAKHE 10:42

And Stephen Hawking's an outlier, right? Like, most people don't live for decades like he did.

ALAN PREMASIRI 10:47

Yes, yeah, he's an absolute outlier. There are only maybe a handful of people I can think of that get even that close to what Stephen Hawking was.

ARYAV DAS 11:02

Yeah. So, you know, we've talked a lot about kind of how ALS has progressed over the, you know, the last, I guess, 13 years and even before that has been exponential. So to kind of go based off of that, what kind of developments are you currently seeing that you are interested in watching over the next several years? And where do you see the field going next? This is going to be a very complicated question for you to answer, and I guess you probably would not be able to give a direct answer, but how close do you think we are to some sort of treatment, or a cure?

ALAN PREMASIRI 11:36

Yeah, that is a complicated answer, and I don't think I can give a good one. But let me try to tackle it by offering kind of like different angles. So there's a few things to be excited about from a research perspective. One of them I already mentioned, which is genetic therapies. So we did have a drug. This drug, it's an antisense oligonucleotide, which is essentially targeting like a mutation, the specific gene and its products down the line to either, well actually it's usually to just repress some of its function because in ALS sometimes mutations produce something that ends up being toxic and so you want to find a way to tamp it down. So there's this gene superoxide dismutase-1, SOD1, that is pretty well known to be linked with ALS. It's been known for like 30 years now, maybe a little bit more, to be linked to ALS. There's plenty of families that have huge family trees that have been affected by SOD1 ALS. And we recently had a drug come out to market called tofersen, or Qalsody, that targets that gene specifically, that mutation specifically in that gene. And there has been shown to be benefit, like symptomatic benefit in people who have that mutation. So that drug took maybe 20 something years from conception to approval to get done. But now that we have that, we have like a model of what a gene therapy and ALS might look like to design and to get approved by the FDA, right? So like, the next one, hopefully, will have taken less time, and we were seeing some of that. There are some drugs in trials right now that are similar, that target different genes, different mutations, that the whole timeline would have been like five years instead, right? So it's like so much quicker now. And I think we're gonna see more of those as we try to understand the genetic links to ALS. So that's one, there's one thing to be excited about. Another one is still just the understanding the biology better. I think all the academic institutes that are going really deep into the core biology of ALS have made a lot of advances in the past five years, five to 10 years with improved assay technology, improved computational technology that has allowed us to understand biological pathways a little bit better, what might be affecting what, different models of the disease. So like cell models, animal models being developed. I think that has generally gotten a lot better. And so I think it will continue to improve at a quick pace. And then the last

angle is, I think, understanding sort of the subtypes of ALS better. So like I said, ALS presents differently in everyone. Where the symptom starts, how fast it progresses, how long people have the disease for, right? So we don't have really a good way to group ALS together. And when you're developing a drug, it helps if the drug is affecting people with similar biologies, right now, we just kind of have to give it to everyone who has ALS, regardless of how their disease started or what the cause was, excluding the genetic component. And so I think we've made a lot of strides as a field. And this is coming from those natural history studies of characterizing ALS into subgroups, at least how they present, and finding good ways to measure progression that improve on what we currently have, which is basically a questionnaire where we ask people on a scale of zero to four, how good are you at cutting food or handwriting? It's a little more scientific than that, but it is basically a questionnaire, but like we're finding ways to measure limb strength better, measure speech better, measure breathing better, so that we can have more sort of like detailed profiles, right, of these people, so that we can actually make the subtype categorization that we need to. And then eventually, hopefully, we can develop the drugs that hit the specific subtypes. So to go back to your question about when I think we'll have a treatment, it's going to vary, I think, depending on where, how we can break down ALS into its different kind of subgroups. You know, we can find another genetic mutation and somebody can develop a treatment for it, that might come in the next five years. Or we find a way to help people who have like limb onset, but really slow progressing ALS. And we find some biological commonality for those people. And we develop a drug for that. And it helps those people. And that can come in the next 10 years, you know, so developing one drug to help everybody. There are still efforts to do that, of course, too. That's harder for me to conceptualize the timeline. That one might be like 15 to 20 years, but it would hit the most people, right?

ARYAV DAS 17:34

So do you kind of see the future as like, almost like personalized medicine more than a general drug?

ALAN PREMASIRI 17:42

I think right now it is the more achievable approach, or at least it makes good use of our time right now than trying to continuously hope that we can make the one drug. Which, again, from a biological standpoint, like we want, we're still studying that. It's not that people are, you know, holding off on that. The issue comes when you do a drug trial. You still are, have in ALS, there are not that many people you can enroll, which makes the power of the study not as good as it would be in, you know, in the condition maybe like diabetes or something where you can easily get thousands of people to join a study and you can get good, good power. You know, there's still going to be limitations just because it is ALS and it's going to be hard to show, unless you just get that magical home run, you know, that a drug will help everybody.

ARYAV DAS 18:42

Yeah, so, you know, to kind of shift this from, you know, kind of like the more research to like more community-based, cause I think a lot of people who are watching this, you know, probably will be normal people who are kind of like wondering like potentially what they could do. So I guess what I'm basically asking

is if like, if someone generally, I mean, you know, donating money is great and like, obviously like we encourage people to do that, but would you say, if someone really cares about ALS but they don't do research and things like that, other than donating money or fundraising, what else do you think the ALS community is looking for? What else could they do?

ALAN PREMASIRI 19:22

That's a good question. Other than donating, which is a good one, because ALS research needs funds, but I think, so I want to say awareness, but I don't want to say just so people know, just so more people know. I would say like awareness about the group specifically. So there's a lot of other non-profits like ALS TDI that just educate people on ALS, that have resources about ALS, that help people find trials. You know, there's a bunch of us out there, and I think there's a lot of people that aren't maybe living in these like really medical concentrated areas like in Massachusetts or in California. If they get ALS, they don't know where to go. Their neurologist might not specialize in ALS. They just might do all the neurological disorders, you know, Parkinson's and MS and everything and then it's just kind of this feeling of being left alone with no hope or like no direction. So the reason I say awareness and not just about ALS but about the groups that exist is it'd be great if people who unfortunately get into the ALS community at least they know somewhere to turn to, like some group to start with. Because once you're in with one of these groups, one of us, you know, we're always talking to each other and we're always collaborating. So we can always connect them with the others. It's just getting to us in the first place. And I think, I think awareness in that manner would be really helpful for the ALS community.

SAMARTH DUNAKHE 21:14

So, thanks for the answer. Kind of going off of that, do you have any recommendations for students like us, or what exactly can we do to raise this type of awareness in our community? What type of like community events can we host maybe to make like a meaningful contribution towards like letting people know more about this disease?

ALAN PREMASIRI 21:32

Yeah, the good thing about fundraising is that you don't really have to you can do whatever you want. Whatever motivates you, whatever gets people out and in front of the information is what will work for ALS. There's not like a specific like, you know, if you're trying to combat some sort of cardiovascular disease, you might want to do like a walk or a run specifically because it kind of lines up right. For ALS, It's really whatever is exciting. I think again, it's at those events, not just saying this is for an ALS fundraiser, but like there's ALS research going on and there's like ALS support groups that exist just to have that little extra resource.

ARYAV DAS 22:25

Yeah, so, you know, I think we've, I think we like grew a lot throughout the interview. And I guess like this, the last two questions we would kind of have is, looking at everything you've seen overall in ALS research and the ALS community, what do you think needs to happen next, in a general sense, to make a real difference for

patients and families? You kind of talked about it in terms of what's happening next in research, but what needs to happen next in the community?

ALAN PREMASIRI 22:56

That's a good question. I don't know if there's like a best, best answer. I think there's probably a few things that need to continue to happen. I think getting education to families in areas, like I said, I'm kind of reiterating a point, but in areas where there's less or underserved like medical attention. So more rural areas of the US areas that are not staffed by people who like specialize in ALS, because in my experience, there are neurologists out there, and it's not necessarily their fault or anything, but they just don't know about what research is going on, what support groups exist, what trials people can get into, and then they don't have any information to provide to the patients. So I think just getting more education out there, and this is something like we're doing, and there's some other nonprofits that are doing too, is connecting with clinics and stuff to give resources to these like neurologists and nurses and stuff, so that they can at least present something to the patients that come in. On a similar note, a lot of the studies, like ours, the natural history studies that exist, in the US at least, are very sort of homogenous in their demographic makeup. So we have a lot of white coastal, like, major city people who join these studies, because they have the information already, their neurologists know where to point people. And so these studies, you know, capture a lot of those people's information, but there are a whole other group, I mean, all the other groups of people. It doesn't matter if you're Black or Hispanic or Asian, you can still get ALS. But we have so much, so many fewer of them in these studies. And so, being able to reach the more diverse populations is also going to be a big thing that needs to happen in ALS because, again, it contributes to the, is this drug going to help everyone or only some people? And if we don't collect the data on the people that we don't have data on, then how are we going to help them too?

ARYAV DAS 25:16

That makes sense, yeah. And then to kind of, I think, just the last question. I think to kind of end off the interview on a positive note. Just to ask, on a more personal level, if you could leave young people like us with one piece of advice about how we should maybe contribute meaningfully to a cause like ALS, whether that's, you know, whether you recommend us going into research, like I know me and Samarth have done a little bit of, or advocacy or, you know, whatever else, what like, what would it be?

ALAN PREMASIRI 25:45

First and foremost, it should always be to do the thing that makes you excited. So if talking to people and spreading the word and being on social media and stuff is something that you're interested in and you're excited to do, like go that route and, you know, go advocacy, find care groups, spread the word. If you're more into research and it's, you know, it's a little bit harder to get started because you need to have data or something, right? So, you know, I would look at the research groups, these academic groups, and then see what they've done specifically, there are datasets, and you guys have worked with a few, that ALS research groups make available really for almost anyone to use. Usually, you need some supervisor or something, but there is data out there. So if

you're a student who's really into coding, or using AI, or building neural networks like you guys have. You don't need to necessarily create your own study or you don't need to have a background in ALS or any other neurological disease. Look for the data sets that exist online and ask for access, download them and just go for it with whatever expertise or whatever kind of passion you have. I would say with ALS, we're still in the space where we can really just use any help we can get, any new perspectives, any skill sets that even come from some other disease or some other job. I think it's still all valuable for any of us. Yeah.

SAMARTH DUNAKHE 27:35

Thank you so much for answering all of our questions. Really, really good answers. Left us with a lot to think about. But yeah. And I think this will be really insightful for the people watching.