



The
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Society™

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EDS ECHO

Alan Hakim, MA, FRCP

The EDS Global Learning Conference 2019 Nashville

Video <https://youtu.be/kSLH-L1nofM>

[00:00:00]

[00:00:06] *[Project ECHO video begins playing – upbeat background music]*

[00:00:36] **Dr. Alan Hakim:**

Welcome, everybody. Thank you so much for joining us.

We are the first. We are the trailblazers, and I very much hope over the coming months and into the coming years, that we'll have many, many more people connecting with us.

[00:01:03] **Dr. Clair Francomano:**

Planned agenda for EDS's inaugural cohort, is the following. There's a place for resources for this ECHO community as well.

Are there questions for Dr. Chopra?

[00:01:18] **Project ECHO Attendee:**

Yes. I have a question.

[00:01:19] **Dr. Clair Francomano:**

And I hope to see you back next week.

[00:01:34] **Dr. Alan Hakim:**

We'll be emailing you and asking you to look forward anything about any of the subjects that we've been discussing. I would encourage you to have a look at Fraser's paper on prolotherapy...

[00:01:46] **Project ECHO Attendee:**

I've passed that information on to other patients and they've been getting more benefit from it.

[00:01:50] **Dr. Alan Hakim:**

This has been a fantastic session. Thank you so much for joining us. As of now, we've gotten past the ninety minutes.

[00:02:20] *[Project ECHO video ends. Applause]*

[00:02:24] **Dr. Alan Hakim:**

Can you hear me? Yes, you can hear me. That's lovely.

So, it's a real privilege to be leading on this. This time last year in Baltimore, we seeded the idea of this. We weren't really sure where it was going to go, and I'm just going to give you a report now, of our experience to date and share with you, hopefully our enthusiasm, and ask a favor of you at the end, so you must all pay attention to at least the last two slides. So, pleasure to be here again with you and to be working with The Society in my. in my various roles.

But, the reason why ECHO came about really, was because we were aware from all of the different types of work that we were doing. Whether it be through our conferences, or through social media and our social networks. Whether it be through our webinars, our website, the publications, the research, the work with the International Coalition and the Consortium, that there was just something – something missing, and, and really that...

...something was the opportunity to share the experience of people very familiar with caring for all different variations of Ehlers-Danlos syndrome with more general clinicians from all different backgrounds, and how might we do that in a slightly different way, that was much more live. Real.

Where we could talk about cases together in a slightly different format, and so the desire to support healthcare professionals in their day-to-day practice was there at the forefront of our mind. How might they access our expertise without having to do the traditional pathway of referral? Which many of you all know is an extremely difficult process. Access for patients, even in areas where there is already expertise, is extremely difficult. Some of us have got terribly long waiting lists and are the only people that are available across a very, very wide geographical space. And how do we generate the opportunity to learn from each other day-to-day with some of those, kind of, those neat little tidbits of knowledge. Is there some way that we could actually share this? That broke down the barrier of distance. We are a global charity. How do we make this worldwide and can we also make this a continuous learning process for all of us? So, we were sat there thinking, well, that this sounds rather grand, and then Lara came up to me and said, “Well have you heard of Project ECHO?” and I was like, “No.”

[00:05:09]

So, we went away and we explored Project ECHO. Now, in principle, Project ECHO is exactly all of these things and it started through the momentum of an incredible man, Professor Aurora, who was a hepatologist, is a hepatologist in Albuquerque, in New Mexico, and he wanted to provide a substantially better service for patients throughout New Mexico, so there were no barriers based on your geography, or your financial ability, or your clinician’s expertise. And so, from that, after a period of I would say at least ten years, this is now a global phenomenon. People around the world are training to become these hubs that are supporting people in networks, to manage their patients at a distance from the expert sites. And there are three guiding principles on this slide.

On your right-hand side, you’ll see that we’ve got moving knowledge, not patients. This whole concept that we can, through technology now, all talk to each other as clinicians, and guide each other through how we might manage our patients without the patients having to physically be in the expert’s room.

The second guiding principle, is this whole idea of a hub-and-spoke. So, people dial in – the clinicians dial in to the, to the hub site, and between us, we’re then all sharing our knowledge. Some of the practical barriers, as well as the knowledge around the medicine and the science. So, commut – people who are providing for care in the community, are able to share their expertise with the specialists. Community teams will be able to share their expertise with other community teams, and just as importantly,

community teams are able to share their expertise with the specialists, so that – because many a time the specialist is probably only going to see somebody once or twice and it's the generalists that are going to manage the patients. So, giving everybody that support.

[00:07:21]

So, in effect, the third principle then is: all teach, all learn.

And this particular schematic is, is put there to demonstrate that the more you have support for clinicians out in the community, the more people we can look after and care for, rather than a few much more elite, if you like, because they have access to the specialists. So, these are the guiding fundamental principles.

[00:07:49]

We are now EDS ECHO. We have established ourselves as the first international hub. So, Project ECHO is very excited to be working with us, because most of these programs are being done at local or regional level. No one else yet is doing it at a global level. So, we are learning, they are learning, and it's a really exciting time for us. We know, because of the nature of our organization and the people that we have networked around us, that we can do this at an international level. We can do this at a national level. Within nations, we know that we have got the network capacity to drill down to your province, or your state, or your county, however you're geographically broken up, and even down to local. And the beauty of this, because it's a virtual program, is we can wrap them all up together as well. We can do all sorts of different programs. So, we joined Project ECHO in the autumn last year. We were extremely fortunate to be gifted the funds to be able to establish the program, and we went live in spring this year.

[00:09:03]

We started off, some of you may have seen this, and it's available on our, our website, with a webinar that just describes this a little bit more, and there was a Q&A. So, if you're interested in finding out a little bit more information, this is available on, on our website as our kind of introduction, and you'll see Lara there, and my colleague, Clair Francomano in the picture, who has been incredible support as the other lead facilitating clinician with me.

[00:09:31]

So, we have commenced, you'd say, "think small," but actually, we've spread ourselves across the globe already by having two hubs – one on the East Coast currently in Baltimore, but it will be moving with Clair when Clair moves to Indiana, and so we'll remain on the East Coast – and one in London, and we, this was our initial expectation. We've already delivered

a nine-week program of experts and case presentations to a group of clinicians from all sorts of specialties.

[00:10:08] But of course, our ultimate long-term aspiration is for that map to look much more like this. That we will, over time, be training more and more people to be able to facilitate from much more regional or even national hubs, so that we just get that spread that we need in the local culture.

[00:10:27] In our first group, we've had an incredible array of interest from different specialties, and this has been fundamentally helpful, because if you want to have a conversation that needs to cover the complexities of somebody's case, the first thing you need is to make sure you've got a multidisciplinary team in the room. So, we've had people who have joined us from their different countries who are chiropractors, clinical psychologists, dieticians, family practitioners, geneticists, internal or general medicine consultants, nursing, occupational therapy, orthopedic surgery, pain medicine, physical therapy, had a paramedic in the London group which was wonderful – somebody now knows how to look after POTS without taking you to the ER – and rheumatology. And the countries that were represented in this first round: United States, Canada, Chile, the United Kingdom, Ireland, Sweden, France, Israel, and New Zealand. And the guy from New Zealand would dial in religiously to every session at six o'clock in the morning his time. How's that for commitment?

[00:11:44] Great set of speakers, many of them you will hear at conference over the next couple of days. Huge support from our speakers, our experts who've been coming to our sessions with us and I thank them all considerably for their support. Not a single one of them came away from the session that they did, not buzzing. They just all thought it was great and I think that's really empowering and powerful as we spread the word amongst our clinical colleagues about the value of this.

[00:12:15] We've had amazing feedback from the people that have been engaged with us, and here's just a couple which I think are really quite heartwarming and really drive home the point behind this. So, I'm just gonna read these out to you:

“Hearing people from different professions and from different parts of the world share insights which threw light on intensely complex case studies. This illuminated how to help some patients with very difficult problems. I found the program truly inspiring.”

“This week was incredibly helpful, the range of cases was very interesting. As a result of presenting cases myself I have gained very helpful insights. Having this platform to discuss cases is invaluable in my opinion, taking specific information and areas to explore with patients as a result of the discussions gives me (and my patients) renewed hope!”

Well, this is exactly what we wanted to start to deliver, so we’re delighted that this is the kind of feedback we’re getting.

[00:13:15] We’re taking our message everywhere. This seems to be a popular picture of Stacey. It’s come up several times. It’ll come up again. Here she is at one of the conferences in Europe and we’re spreading the word everywhere we go with our conferences.

[00:13:31] We are developing three particular kinds of program. We’re thinking of the specialty programs. So as well as more general training and support for people, there are areas of subspecialty, and I’ll talk to you about the four that we’re going to focus on first. The geographic programs, is this concept of the spread, the global spread that I showed you in the map, and then more recently something that we didn’t expect to happen, but people have raised interest, is something that we’re causing – calling the organizational program. Here we have healthcare organizations, existing structures, I don’t think I’m at liberty to name the names at this stage, who are very interested in how they might support their clinicians to run better services for our patients with Ehlers-Danlos syndrome, and so we are ready to build a spoke education and support programs to allow these clinicians to do this from their own organizations, and I think that will be incredibly exciting as, as we launch that.

[00:14:3] On the specialty program side of things, just to give you a flavor, we are looking to establish the Vascular EDS ECHO later on in the year, and this will be a focus in particular on vascular EDS and the other rare types of EDS, where there are the specific vascular issues of aneurysmal and dissection disease, and this will be something that will run for any clinicians who have challenges, difficulties in managing their patients internationally. Again, for orthopedics. Again, for physiotherapy. And again, for pediatrics, and we’ll probably be running the pediatrics initially out of Australia, because we really want to spread the, the distribution of the hub.

Now I think some of you will have also heard at the affiliates meeting or maybe one of the other meetings that’s happened this morning, that we are really interested in growing other forms of education or, or tu – a kind of

tutorial type programs. And one thing that we really want to explore, that we're just working on at the moment, is the whole idea of supporting our volunteers, our advocates – so, our patient group and, and their carers, and how we might actually develop a program of support that runs in exactly the same way that the medical program works, but, but for, if you like, lay people in the sense that it's our patients and our carers that are learning to become advocates and volunteers. So, the opportunities are protean.

[00:16:11] So, this is the bit you have to truly focus on in order to help me. On our website, there is a whole section on EDS ECHO. I encourage you to go there and just have a quick look to kind of pick up the jargon and the language around hubs and spokes and what we do. <https://www.ehlers-danlos.com/echo/> I was at the Old Opry a couple of nights ago, and it's a radio show, if you don't know, and I was thinking, I would really like to do this exactly like the old Opry.

[In the style of The Grand Old Opry host]

"So, everybody. We'd just like to introduce you to EDS ECHO, and we'd like you to go to <https://www.ehlers-danlos.com/echo/> – Take a good look and come on down!"

[Laughter]

[00:16:59] Thank you! Now, what you really need to do though, which is the favor I need, is you look at the bottom of the screen there, you'll see, just if you squint, there's a little thing that says, "Download the PDF flyer."

[00:17:11] And when you download the PDF flyer, this is what you'll get. And please, take this to your doctors. Take this to your therapists. Get them engaged in the opportunity for them to join our network. If we can all do this with two or three of our clinicians, then we will already have a massive marketing campaign in place to introduce colleagues to the, the network. They go – they can go online and they just need to follow the instructions to see how to join us.

[00:17:46] So, I really just want to finish by thanking Lara, who's been an incredible support on the management side of things, leading with me. I think we've had a we've had a blast so far and we know there's lots more to come, so we're really looking forward to it. I'd really like to thank Clair Francamano for huge amounts of support in making this work on the East Coast. Thank you, Clair. But in particular, Stacey Simmonds and Angela Ballard. I think they might be back out dealing with reception and HEDGE, but they have been

phenomenal in dealing with the administrative elements of this. And then, very finally through Penn State University, we've got incredible support from Dr. Rebecca Bascom and Dr. Sh – Jane Schubart. We are looking at the impact of this on people's skills as clinicians and we're also looking at the impact of this in terms of patient's perception of their improvement in their well-being after their doctors or their clinicians have been through this program. So, this is a really important part of our- of our agenda.

[00:18:55]

So, without further ado, I'd like to say thank you very much for listening, and I'm going to hand back to Lara.

[Applause]
