Second Annual Community Symposium on the Molecular Basis of ME/CFS
September 29, 2018

Welcome: Linda Tannenbaum, Founder & CEO/President, OMF

https://www.youtube.com/watch?v=2VTWKQfuH0g&index=2&list=PLl4AfLZNZEQPxjqF4ojAO3wdCFMeriNBK&t=2s

Linda Tannenbaum: Thank you very much. Welcome.

We're really excited that you're here today and thank you for coming to our Second Annual Community Symposium here at Stanford University

We have about 300 or so attendees today, as scientists and clinicians. We have people who have ME/CFS and we're really glad that you're able to join us today. We have parents and we have caregivers and we have thousands visiting us and watching on live stream from all over the world, so welcome and thank you for coming.

We're going to be taping this, so you can watch it and share it later with others. We want you to know that it's going to come up on YouTube in a little bit so that you can rewatch it.

As you can see, without collaboration research stands still. That's what this week is all about.

We had some wonderful scientific meetings this week and the whole point and the reason we're here today is for open collaboration, so we could really fast forward answers to solve this horrific disease.

You're going to be hearing from an esteemed panel of speakers today, really giving an update on the molecular basis of ME/CFS.

You're going to leave here with a lot of hope that a lot of research is happening.

I started Open Medicine Foundation for the purpose of open collaboration, of facilitating and funding scientists to get together, scientists to do research and really pull it all together to find some answers. Because with people who have, and patients who have, ME/CFS the one and most important thing that matters is that we really find effective treatments and hopefully a cure someday.

For those people who have no idea what they have and they're sick the most important thing that matters is that we find a diagnostic tool and that we find a way to diagnose them so they don't have to keep going to doctor to doctor to doctor and not know what they have. For everybody else, it's that they don't ever have these horrific debilitating diseases ever, so prevention. We have a lot to do and we have a lot of research going on to get us to that path.

To quote Helen Keller, "Alone we can do so little. Together we can do so much."

These are a few pictures of last year's Symposium and, as you can see, in the center is my husband and I on the bottom. On the top left are the Davis and Dafoe family.

I want to take the time to thank a few people who are here today, starting of course with the Davis and Dafoe family and please hold your applause just for a moment. I want to thank Dr. Ron Davis especially, for building and leading a phenomenal research team and for bringing people together and really encouraging people to come together, to share, openly collaborate, share their research, and really work together to find answers.

I want to thank Ron's wife Janet Dafoe, who works really behind the scenes, effortlessly connecting with patients, helping everything that we're doing. As parents on a mission, as my husband and I are, and the Davis and Dafoe family are, and many of you are parents. We're on the mission of our lives to cure our kids and to get them back to health. We have to step up and do this.

I'd also like to thank Ashley Haugen for planning this unbelievable conference, science days, all the details, all the logistics, everything that was today, everything that happened, she did every detail seamlessly. Thank you very much for doing this again.

I want to thank Whitney Dafoe. Although he doesn't know it yet, he has inspired the world and the patients to hold onto hope, because we are going to find answers. Please, join me in thanking the Dafoe Davis family.

(Applause)

We couldn't do what we were doing without our dedicated team. This is our Scientific Advisory Board, our OMF Scientific Advisory Board, and I want to thank you all for your input, for your engagement, for your dedication, because you've really helped us all take research to a whole new level.

I'd like to ask our Scientific Advisory Board to stand, who are here in the audience today, and all of the scientists and clinicians who joined us the last three days with our phenomenal scientific meetings that we had. Please stand, if you may. We'd like to thank you all and we'd like the patients in the community to know that there's so many people who care about them

(Applause)

Thank you so much.

We did have three full days, so we did have many, many more scientists and clinicians that were joining us in the three day science meeting. It was really amazing to hear everybody share ideas, openly share their research. Thank you all for doing your research. Thank you all for sharing. This is what it's all about, to get together and work together to make this happen.

I'd like to ask our OMF team to stand, if you may. This is the strength behind the scenes. Our Open Medicine Foundation Board, our Open Medicine staff, all of the people who volunteer with us in any way at all, please stand so we can acknowledge you and thank you.

(Applause)

Thank you so much.

Lastly, and actually most important, are our patient partners. We couldn't do any of our research without patient samples, without patients really helping all the other millions out there that are suffering. We want to acknowledge them and really thank them very much. Some of you are here, some of you are listening, and we always need people that have ME/CFS to volunteer. We need healthy controls. If you're local we really need to ask if you would like to join us. We have the contact information at the bottom here, info@omf.ngo. If you'd contact us, so we can draw your samples and continue our research. We thank you so, so much and so very much, thank you.

(Applause)

When I began Open Medicine Foundation there really wasn't much research going on and, as you know, the government hasn't been funding all that much research either. Without funds there wasn't a cure in sight whatsoever.

When we put this together, first we needed to get some researchers that were interested in researching ME/CFS. Well, that we have. We have a lot of researchers that are researching this all over the world and with our teams. This is an international problem, so we needed to bring patients together and let people know what we were doing all around the world. Now we have that and we're really excited about that.

Then we needed to bring people together and the scientists together to openly share their research, so that we could really move this research forward. That's what we did this week and that's what other people are doing with certain conferences, because we all have to share openly to make this move quickly.

The hardest part is raising money to get this going, because we want to do your research as much as possible and as fast as possible. We are tremendously grateful for all our supporters and our donors that are here today and that are listening to us. We could not do any of this research without you, so we thank you from the bottom of our hearts to be able to do all of what we're doing and all that everybody's doing with their research.

Both large and small donations led us to raise over $15 million for research these past few years. You might have read our exciting announcement last January. We got an anonymous $5 million dollar donation from a Bitcoin investor by the pseudonym of Pine, of the Pineapple Fund. We are grateful and, if you're listening, we thank you very much. This was incredible to be able to have. Now we've been able to increase our research tremendously from that donation, of course, and other donations.

Because of the generous community we've been able to fund over 15 different projects at Stanford University, Harvard University, Uppsala University in Sweden, University of California San Diego, and many others.

We've established two ME/CFS Collaborative Research Centers, one at Stanford University and now we've established one at Harvard Medical Center and affiliated hospitals.

To analyze all the data we've developed an open data platform that researchers can now go on our website from all over the world and access our results.

We're fortunate enough to raise funds that we have and we have funded a multitude of really important projects, but now it's really time to step it up. We are truly trying to raise $50 to $100 million a year and until the NIH kicks in gear we need to do it ourselves. Together, we can fund all this research in a very large, collaborative way.

Leading research and delivering hope. We will continue until we find answers. Thank you very much.

(Applause)

Greetings: Janet Dafoe, PhD, Patient Liason
https://www.youtube.com/watch?v=SrMs6gW_tnk&index=3&list=PLl4AfLZNZEQPxjqF4ojAO3wdCFMeriNBK&t=0s

Janet Dafoe: Welcome to all of you.

I am so glad to be here. It just warms my heart and breaks my heart to see all of you patients there. How many of you are patients?

Well, I want you to know that I carry you all in my heart and all the patients that are watching this and all the caregivers that are here. How many are caregivers? Thank you so much. I really know how hard that is and how much love it takes to be dedicated to your sick family member or friend. It's really amazing what you do.

On the internet I promise to give hugs. I'd just really like to hug any of you who feel like having a hug.

(Audience laughs)

Anybody for the virtual hug of the people watching this, I just give you a virtual hug and I pray. I know from this research, from knowing my husband, and seeing the researchers that he's brought in. It's so incredible, if you could have been there. He keeps bringing in more and more incredible, really smart people from all different areas. People that yesterday and the last three days were so dedicated and interested and the more they sat there the more energized they got. They'd stay during all the breaks and dinners, talking about all of their new ideas and it was just buzzing. They're excited about what's happened so far. I just want to convey to you the sense of hope that I felt being there for the last three days with these incredible researchers.

We can't do this without the doctors. We've had a lot of contact with a lot of doctors seeing Whitney and some of them are weird, some of them are kind of ADHD, some of them are kind of whatever. They walk in that room with Whitney and every one of them are the most beautiful, gentle people with him. Bob Naviaux came in and saw him last night and Whitney just relaxed and I just thank you to the doctors.

I want to honor one in particular today, which is Cindy Bateman. If you would just come up here.

(Applause)

Cindy, she collaborates with everybody. She's so smart, she is so dedicated, she is so compassionate. She is running all this, continuing medical education, and trying to get all of the doctors together to figure out the message for all the other doctors, what to do about this. That's just the shortlist of what she does, but the coolest thing that she does is she has this wild socks thing. She's wearing wild socks until we figure this disease out.

I want to help her out.

(Audience laughs and applauds)

Cindy Bateman: Oh, yay.

Janet: Here is starry skies.

Cindy: Excellent. Woo.

Janet: Here is some pandas. Here is ... Oh, there's two of these in here.

Cindy: My, my.

Janet: Some cool Native American ones.

Cindy: Ooo.

Janet: Here is just some ... I don't know. For Saint Patrick's Day or something.

(Audience laughs)

Here are some ...

Cindy: Wow.

Janet: Here's the extra.

(Audience laughs)

For your other foot.

Here is some warm fuzzy ones to wear without shoes.

Cindy: Cool.

Janet: I have to say you'll notice that some of these are lightly worn by Ashley, but ...

(Everyone laughs)

But I couldn't give them away to anybody but Cindy.

Cindy: Aww.

Janet: Thank you so much to Cindy and to all of you.

(Applause)

Cindy: Thank you. Thanks.

Janet: Oh, alright. My next job.

(Audience laughs)

Okay, now I have the extreme pleasure of introducing the best person in the world, except maybe for Ron, which is my wonderful daughter who is just so dedicated. You know, it was her idea to have Whitney be the poster child person for this disease. She's done an amazing job with this conference and being dedicated and coming over and helping with Whitney whenever he wants her.

This is Ashley.

(Applause)

Symposium Logistics: Ashley Haugen, Event Organizer
https://www.youtube.com/watch?v=m3oRdfYhGOg&index=4&list=PLl4AfLZNZEQPxjqF4ojAO3wdCFMeriNBK&t=0s

Ashley Haugen: Hello.

I just want to, first, thank everybody for coming. I know some of you have traveled from really far away from other countries. We have like 3,000 people watching on live stream as of right now. It's just really incredible. I am so proud to be here and be able to run this for you guys and I am just so grateful for today.

Seven years ago, when my brother and I were first just dreaming up what we wanted for this disease, how we wanted to contribute, and how we could help our dad find answers, we talked about our big goal. A goal that neither of us thought actually attainable, but figured why not dream big. That goal was this Symposium.

Thanks to the funding from Open Medicine Foundation and to all of the dedicated scientists that are here today, we are able to see our dream become a reality for the second year in a row.

I cannot believe the dedication to this disease that I see before me. It is something that will someday go down in history.

Me I just want to thank you guys so much for coming.

(Applause)

Just have a couple of logistics for the day. We have so many questions for all of the speakers and we want to be able to include the people that are watching on live stream remotely, so instead of having quite Q&A, we're gonna do panel discussions. We're gonna do one after all of the morning speakers, before lunch, and one before we close, after all of the afternoon speakers. You can submit your questions online and it's up here: omf.ngo/questions. You can submit them all the way up until the panel begins.

Raeka will be gathering all of the questions and going through them and asking the panel for you guys. This is the best way to get through as many as we possibly can, because we want to answer all of your questions.

Next I would like to introduce my father, Dr. Ron Davis, but before I do I'd like to just say a few words about this man. He works tirelessly on this disease. When he isn't helping my mom care for my brother he is reading articles, brainstorming, talking with other scientists, using his connections and friends to get as much work done as he can, simply on favors because of the lack of funding. He spends every hour of the day, and I mean every single hour, thinking about this horrible disease and trying to get a cure for all of you.

One day I asked him why he didn't ride his bike to work anymore. He told me that he is afraid to ride it, because if he were to fall or get hit by a car then who would be here fighting for the patients, for his son?

Everything that this man does in his life revolves around curing all of you and curing my brother. There is not enough gratitude in the world to give to someone who gives over their life for others.

Before we get our day started I just wanted to say thank you to my dad, a true hero fighting for everyone around the world with this disease. Now, without further ado, I'd like to introduce you to Ron Davis who, as I said last year, my brother and I so affectionately call Ron.com, because he is always better than Google.

(Audience laughs)

Ron.

(Applause)

Thank you to our volunteers for providing these transcriptions.