

Closing Remarks- Ron Davis

<https://www.youtube.com/watch?v=ucr785xQSII&index=18&list=PLI4AfLZNZEQPxiqF4ojAO3wdCFMeriNBK>

Ronald Davis: Well, one thing that's been pretty striking is the fact that the Open Medicine Foundation has been several years ahead of NIH.

(Audience laughs)

They gives every great deal of credit for all the effort that goes into this. Also the patients and the caregivers and donors deserve a tremendous amount of credit for all the things that they have done, either in giving blood or giving funding. It's really made it a real big team effort and I got to say I was optimistic at the end of the last meeting we had, because it seems like we were making ... going in the right direction. I still think that that's true.

When we looked at all these different pictures of the disease that different people are looking at I don't think that there's got to be one right and all the others are wrong. Good chance they're all right and we just don't know how they fit together.

This whole thing is like putting together a massive jigsaw puzzle. There is different people putting together different patterns and they keep expanding it and eventually the pieces are all going to start fusing together. We're not there yet. We don't know how they fit together. My suspicions are they all will fit together and they're, all of the components, will be really important to understand. That's why it's really important that we have different expertise and different viewpoints and different information being collected.

The important thing is that people do good experiments. They challenge themselves. They make certain that things are correct, 'cause that can derail the field. But I think that that's what I see happening is the right thing is happening in this field.

It's hard to understand what we're going to be doing next year. I think this has been a successful thing to do and so we're going to try to raise the money. No, Linda is going to try to raise the money (all laugh) to have another meeting like this next year and a community symposium. 'Cause I think it's very worthwhile.

I think it probably is time to thank people that have done such a great job.

Good, okay. There've been a lot of people that have made this possible. They certainly haven't been in the background, because you keep seeing them running around (laughs).

First of all, I would like to ... I think I would like to start with Linda and thank her with the Open Medicine Foundation, 'cause she started an awful lot of this.

(Applause)

And pardon? Linda (laughs). Come on up here, Linda.

Linda Tannenbaum: Thank you.

Ronald: Thank you very much. I remember ... how many years ago was it?

Linda: You and I?

Ronald: Yeah, the two of us sitting in our living room four years ago. Where you said, "You know, I know how to raise money, but I don't know who to get to work on this."

And I said, "I know who to get to work on it, but I have no idea where the money is coming from."

(All laugh)

Then there's all of a sudden it's obvious: we have to work together. That was actually a wonderful moment, because it really set the direction, what we really have to do.

Now, the other person I'd like to thank is, and you've seen quite a bit of her ... Boy, isn't she witty? Raeka has an incredibly fast mind, so don't try to pull a fast one on her. She'll get you.

(All laugh)

I'd really like to thank Raeka. Come.

(Clicking applause)

Thank you very, very much (inaudible) your wonderful job. Wonderful job.

Now, there's another person that you haven't seen that much of, because she is in the background doing an unbelievable a number of things. One of the problems that we've had in the last several months is the fact that we've lost our financial person and so somebody has to take up the slack. It's largely been Katrina. Then we've lost our Communications Director, Raeka and who has to take up the slack? Katrina.

(All laugh)

I get ... I don't know what it is 65,000 emails every day. Who has to look at them? Katrina.

(All laugh)

Those are just her part-time job (laughs). Then she has to run the lab and and take care of all the students and all the other scientists and get what they need. So I wouldn't be surprised if she was back in the office because there was something urgent that she had to take care of.

She's done a lot with this, all the peripheral kinds of things, and she's helped out doing an awful lot of stuff, especially with the email links that have to get done and so forth. 'Cause one of the problems with working with geeks; they don't read email.

(Audience laughs)

They don't answer the phone and they don't read real regular mail.

(Audience laughs)

So it's hard to get ahold of them (laughs) and just to invite them to the meeting is a major undertaking.

We've had to figure out strategies to do that by knowing who the speaker's significant other is and then find a friend of that significant other, right? And then find the someone that can communicate with that person and that's how we get ahold of most of the people.

Ashley Haugen: She's also a scientist.

Ronald: Yes. That took a great deal of skill. Now on top of all that she's also scientist. (inaudible) scientific meaning she totally understands what we're doing. She has a great spirit of just wanting to help. What needs to get done? I'll do it. She's been, I think, the best person I've ever had working for me, because she understands what needs to get done and she does it. It's just been wonderful having her, so I really want to thank Katrina. You haven't, probably, even seen her, because she she's always been in the back out there.

So Katrina, thank you very, very much. Wonderful, you were just wonderful.

Katrina: It's a pleasure working with you.

Ronald: Now, the other problem is how do we put on a meeting like this? If it were up to me it would be an absolute disaster (audience laughs), because I would forget all all sorts of things, like have the meeting and then someone says well, where's the food? And I, oh, food? We have to have food?"

(All laugh)

And so it's really good that I didn't try to organize this, because I'm a nerd and so it would be just the science.

Fortunately, we have Ashley Haugen and she really did all of the organization. Katrina helped her on lots of the logistics with the lab, but she took care of all of the three day scientific meeting single-handedly at the meeting, organizing everything, organizing all of this. Where are we going to do it? She I had to deal with Stanford, for gosh sakes (all laugh) to try to get this done, which is not an easy task 'cause there's so much who's in charge, right? You never can (inaudible) to figure that out.

Anyway I really want to thank Ashley, made this really possible. What I have noticed about her in organizing the ... Why I had got her to do this is that she got married a couple of years ago and she organized her own wedding. Not a single flaw. Not a single one. Everything ... well, except for the drunk, right? But it wasn't your responsibility.

(All laugh)

You had no responsibility for that.

Audience member: (inaudible) the drunk DJ.

Ronald: Yeah, it was the DJ for the ... Anyway.

(All laugh)

It impressed me that this is not an ... Obviously can't be inherited, right?

Audience member: (inaudible) people contributing (inaudible).

Ronald: Oh, there's another person, isn't there?

(All laugh)

And it's probably dominant. I just really want to appreciate the fact that all this incredible organization has been done. It really helps if things don't go wrong and the projector actually works and things like that. Anyway, she's done a fantastic job and I really want to thank her for this. So thank you, Ashley.

And she loves sunflowers.

Ashley: Thanks.

Ronald: (Laughs) Thank you.

I want to also acknowledge Janet, who does an awful lot of stuff with the the patients and she came up her earlier to do stuff and she works very long ... a lot of time helping out with the patients. It is in her skill set, she's a clinical psychologist and she has a PhD in psychology, so when you talk to her she's probably diagnosing you.

(All laughs)

Audience member: You have CFS!

Raeka Aiyar: I think that we're not the only ones who deserve thanks.

I think the main people that deserve thanks right here are you, Ron, and Janet, for making all of this possible and for your tireless dedication to this community and this disease, so thank you both very much.

Come on up here.

(Clicking applause)

Ronald: Thank you.

Janet Dafoe: Thank you.

(Taps on microphone)

Raeka: That was loud.

(All laugh)

Janet: We're all gonna get better.

(Clicking applause)

Ronald: Thank you. Thank you. I think that's it, isn't it? What did I forget?

Raeka: That's it. I'll take care of it.

(All laugh)

I want to close by thanking all of you for making this possible, for making this a truly special event. We really appreciate your engagement and your enthusiasm. It's such a unique community and we're lucky to be researchers getting to research with such a great group of patients, caregivers, physicians, and supporters.

Thank you all and I think that's a wrap.

We have a reception outside for those of you here. For those of you at home I hope you'll toast us from your homes. But please join us outside and enjoy yourselves. Thank you all so much.

(Clicking applause)

Thank you to our wonderful volunteer transcribers for transcribing the Symposium.