

# “End ME/CFS” Mega Chronic Fatigue Syndrome Project Begins

Now *this* is exciting.

The Open Medicine Foundation (OMF) has announced it has created and is raising funds for a huge “End ME/CFS” project. They’re looking for **five million dollars a year** to fund it — about double the NIH’s current annual spending on all ME/CFS research. That’s a **really** ambitious project. Could they actually pull it off?

| *“What is needed is a total attack on the problem.” – Ron Davis PhD*

Bigger is better when you have the kind of brain trust Ron Davis has gathered.

I think they could, and the reason why starts with Ron Davis PhD, the originator and leader of the project. Davis has been thinking about producing a high-level consortium to attack Chronic Fatigue Syndrome (ME/CFS) for years. The idea of a consortium immediately came up when I first talked to him about three years ago. His son, Whitney, had introduced us. Whitney was quite ill then, but since then has gotten much worse. He now has one of the worst cases of ME/CFS I’ve heard of.

In order to understand where this project is coming from and why it might work let’s take a look at the man behind it.

## Dr. Ron Davis

| *“He’s a frequent provider of disruptive core technologies.”*

Ron Davis PhD has directed the [Stanford Genome Technology Center](#) for twenty years. He has a long list of firsts by his name including one – using restriction fragment polymorphisms to construct genetic linkage maps – that helped launch the field of genomics in 1980 and ultimately made the Human Genome project possible.

He’s won numerous awards and prizes (Eli Lilly, Distinguished CIT Alumni and NAS Awards and Dickson, Gruber and Warren Alpert Foundation Prizes). He won the Lifetime Achievement Award from the Genetics Society of America **ten years ago**. PubMed lists over 500 publications for Dr. Davis – the most I’ve seen for a researcher.

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One researcher wrote that Davis’s contributions to the field of genetics are so seminal that it’s impossible to quantify their impact

At the presentation of the Warren Alpert Prize last year Harvard Medical School geneticist Clifford Tabin concluded that Davis’s contributions were so seminal in the world of genetics and disease that it was “impossible to quantify the impact” he and his colleagues had had.

One nominator for Davis’s Gruber Prize stated Davis has “provided the indispensable infrastructure that has driven the astonishing pace of genetic discoveries, as well as provided key technical, intellectual and conceptual contributions to a breathtaking range of genetic problems.”

In 2013 Davis was pegged in an Atlantic Monthly article as one of eight inventors tomorrow's historians will consider the greatest inventors today. "He's not just a one-hit wonder," said Church. "He's a frequent provider of disruptive core technologies."

Frequent is the word. Three years ago Dr. Davis talked about the urgent need to assess the role the HLA region of our genome plays in ME/CFS. No one, however, had been able to figure out how to analyze this very complex region of our genome. In the interview below he reports his lab has developed a low cost means of doing that.

It's safe to say that nobody with this kind of background and reputation has worked in the ME/CFS field before .

## The Biggest Challenge

| *"I really enjoy working on problems that others think are unsolvable." – Ron Davis*

Now Davis is engaged in the biggest challenge of his career: solving Chronic Fatigue Syndrome. He's best known for his ability to devise creative solutions that clear up technological impasses. He likes nothing better than to attack complex problems.

With it's diverse population, it's many unanswered questions and it's lack of funding beating ME/CFS is the biggest challenge of Davis's career.

He's got one now and not just at a technological level. The other stuff was easy compared to solving the mystery of a disorder that isn't well-defined, is mostly ignored by the powers that be, and that has had a spotty record of research.

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Davis believes both the field and medicine itself are ripe for breakthroughs. He's been making the rounds telling everybody that ME/CFS is **the field** to be in now. This is the place to make big breakthroughs that resonate throughout the medical field. He is convinced that cracking ME/CFS will not just solve ME/CFS, but will provide key insights to the other puzzling neuro-immune disorders that dot the medical field.

## Heavyweight Group

The idea is to get experts from inside the field and from outside the field. The ME/CFS experts will lend their deep knowledge of this field. The experts from outside the field will bring a rigor and creative approach to problem solving that has made them experts in much larger fields than ME/CFS.

He's gathered a group of heavyweight researchers to help him..

Thus far Davis been able to gather a group of partners the likes of which we haven't seen before in ME/CFS. The Scientific Advisory Board includes (and the list will grow over time to include ME/CFS experts and more outside researchers):

- [Mark Davis PhD](#) – (170+ publications) runs own immune lab ( [The Mark M. Davis Lab](#)) at Stanford. One of the things he's doing is characterizing what a normal immune system actually looks like.
- [Mario Capecchio PhD](#) – (200 + publications) molecular geneticist and Nobel Laureate and Lasker prize winner

- [Craig Heller PhD](#) (150 + publications) – Stanford exercise physiologist and the inventor of “the glove”, a device that reduces body temperature in order to increase muscle performance.
- [Baldomero M. Olivera PhD](#) (300+ publications) – a University of Utah neuroscientist focusing on how the ion channels and receptors affect nervous system signaling.
- [Ron Tompkins MD, ScD](#) – the leader of the sepsis consortium Dr. Davis participated in, Dr. Tompkins (350+ publications) has produced ground-breaking work on the process of inflammation.
- [Andreas Kogelnik MD, PhD](#) – ME/CFS expert and founder of the Open Medicine Institute.
- [James Watson PhD](#) – the Nobel Prize laureate who, with Francis Crick, uncovered the structure of DNA.

How many boards boast two Nobel Laureates? No one has ever brought this much brainpower together to study ME/CFS before.

## An Emphasis on Rigor

“We wanted the right answer no matter whose theories we destroyed.” – Ron Davis on the Trauma Consortium

Ron Davis is a stickler on scientific rigor. Time and again in our discussions over the years he’s emphasized the need not to be beholden to any preconceived notion – to be open to where the science leads you.

In this process you put everything you know or think you know about ME/CFS at risk. You’re ruthless in your quest for the truth. Instead of trying to **prove** something is right, your first goal is to find the chinks in a finding’s armor. It’s like looking at a diamond. You hold it up and look at it from every angle to find any flaws. Then you attack the flaws. Anything that makes it through the fire of this kind of rigorous inquiry is rock-solid. You can bank on it.

Ruthless analysis and rigorous experimentation allows seminal findings to emerge

Then you figure out your priorities. If it requires creating new technology (and it will) you do that. You gather a large number of representative patients and focus on them throughout. Then you find the best experimentalists in the field and you have them do the lab work. You gather another large cohort of patients and validate the findings.

At every step you use the best technologies, the best materials, the best study designs, and the best researchers.

This kind of research is the antidote to the recent AHRQ report which eliminated 90% of the studies it gathered up for consideration because of methodological and other problems. It’s about producing findings that stick. It’s about producing seminal insights the field can build on for years.

## Expect Surprises

“We discovered that the main theory of trauma taught in medical schools was totally wrong.”

Don’t be surprised if their efforts don’t overturn some ideas regarding ME/CFS. In fact, **be surprised** if this effort doesn’t yield completely novel ideas about ME/CFS.

Expect entirely new ideas to emerge

It wasn’t as if trauma was an unknown entity when the Tompkins group took it on. It had been studied extensively – just not in the comprehensive manner his group used to look at it. It turned out that lots of the ideas regarding trauma and sepsis were wrong.

By the time this consortium has completed its mission, you can expect a new field to emerge. Expect ME/CFS to be completely redefined. Expect several subsets or perhaps disorders inside of it pop out. Expect them to illuminate numerous pathways that lead to the production of “ME/CFS”.

## Mega ME-CFS Project

*“I really enjoy working on problems that others think are unsolvable, and I’ve been finding, to my surprise, that the older I get, the easier it is to take on those problems.” – Ron Davis*

This is research on a different level than we’re used to. It’s a \$5 million **a year** project. That sounds like a lot of money. For ME/CFS it is a lot of money – about double the federal funding for this disorder – but it’s not a lot of money for the NIH. It’s not a lot of money for medical research, and it’s definitely not a lot of money for an often disabling disorder that affects a million people or more in the United States and many millions more across the world.

Community support is needed.

Still for anyone else, given where ME/CFS is, it might seem like a pipe dream. But this is the man who created the technology that made the Genome Project possible. This is the man named as the most likely person in the medical field to be designated one of the greatest inventors of his time. This is a man whose son has one of the most severe cases of ME/CFS you’ll ever find. If anyone can solve the multitude of puzzles that constitute this disorder, he can.

He’s going to need help. Davis is not a rah-rah kind of guy. He’s an inventor, not a publicist. Give him the tools and I’m confident he can engage the collaborators and invent the technologies we need to crack this disorder, but he needs our support.

This is a long-term effort. Don’t expect answers overnight. New technologies will need to be developed. But give this Consortium the funding and time it needs and it’s hard to imagine it **won’t succeed**.

**To support the project go to [www.openmedicinefoundation.org/ways-of-giving/donate](http://www.openmedicinefoundation.org/ways-of-giving/donate) or contact us at [donate@openmedicinefoundation.org](mailto:donate@openmedicinefoundation.org).**

## Dr. Davis Talks

*“The millions of suffering ME/CFS patients are owed an apology and a concerted urgent effort to find effective treatment” Ron Davis*

About six months ago I asked Dr. Davis to answer a few questions:

**You’ve been engaged in high-level research at Stanford for many years. Now you’re working on ME/CFS. What is different about working on ME/CFS field as opposed to other fields? Another way to ask this is, “What is missing in ME/CFS which is present in other fields that is keeping the ME/CFS field from progressing the way other fields do?”**

What is missing in ME/CFS research is long-term stable funding. Short-term funding is okay for specific small projects, but what is needed is a total attack on the problem. This includes developing new technology, which may take time.

For example: a number of laboratories have measured gene expression from cells in the blood. However, blood is a complex mixture of many types of cells. It is obvious that gene expression from every cell type in the blood

measured independently would be much better. It could give us more information and may yield a molecular diagnostic test.

In the last couple of years Davis created not just the first way to study the HLA part of our genome, but he created a cost effective way to do that as well.

Unfortunately, there is no technology available to reliably accomplish this for every cell type. This technology needs to be developed. It is important to note that this does not have to be solely funded by ME/CFS research dollars because the technology is generic and is useful for many diseases.

For example, we are currently sequencing the HLA region in the human genome. This region controls many aspects of the immune system. It's a very complex locus and is not revealed by "whole" genome sequencing. We have developed a very accurate technology that can sequence this region at very low cost. This technology was developed using funds from the Navy and NIAID. Now it can be used in ME/CFS research at very low cost.

Another serious problem is there is no molecular diagnostic test for ME/CFS. This can result in grouping similar diseases into one group. Such a heterogeneous grouping will make it difficult to get unique quantitative molecular information and understanding of what is wrong. This problem is confounded by each set of investigators collecting a new set of patients for every study. It would be far better to have one large set of patients that is used for every study. Validation would then be done on a second or third large set of patients.

The problem is further complicated by having a loose and non-specific definition of the disease. Including patients that have some of the symptoms but not the disease can result in considerable confusion about treatment. If treatment helps those patients with some of the symptoms but not the disease and does not help those with the disease, this could result in a mistaken mandate that all patients be treated in this manner, which could actually harm those with the disease.

**You've worked in Consortiums before and would like to put one together for ME/CFS. What can consortiums accomplish that individual researchers or even research groups cannot and what kind of consortium do you envision for ME/CFS?**

A ruthless commitment to truth exemplified the Trauma consortium's work. It overturned several established theories on trauma and inflammation

For 10 years I worked on a large consortium (Inflammation and the Host (human) Response to Injury) funded by the NIH (NIGMS) and involved 16 laboratories (most of the laboratories that worked on trauma) in the US. It was chaired by Ron Tompkins, MD, at MGH. He did a marvelous job and I think this should be the model for other consortiums. I was the head of genomics for the project. We all met at the O'Hare Airport (Hilton) every 3 months to go over new data and plan the next experiments.

There were several principles that we used.

- We wanted the right answer no matter whose theories we destroyed. Some of our results have upset a number of researchers. But we have a massive amount of data supporting our conclusions.
- We wanted the best experimentalists to do the experiments. When we did not have the best we recruited the best. Not everyone in the consortium had to do experiments. In fact very few of the members did experiments. Everyone had to come to the meetings and share their knowledge and expertise and give suggestions.

- All these contributors were on all the publications. This last point is very important. At the beginning many researchers wanted to collect their own patients and collect their data in their own laboratory. This would have been a disaster. The experimental variance by this method would have been so great that it would have obscured most of our results. In the end only a few researchers collected data (~10% of the group). It is one of the largest and best molecular data sets ever collected on humans. Aside from the hundreds of thousands of facts about individual genes, we discovered that the main theory of trauma taught in medical schools was totally wrong. We also found that the mouse model for trauma used in research laboratories throughout the world showed no relationship to human trauma and should not be used to model human trauma.

I think something like this consortium should be used for ME/CFS. It should include physicians that treat ME/CFS patients. It should also include the best experimentalists and thinkers from several scientific disciplines regardless of any experience with ME/CFS.

The ME/CFS community is owed a concerted effort to understand this disorder and find treatments for it

This group should work together to design a total attack on ME/CFS and focus on understanding the disease, finding diagnostic markers, and devising treatments.

Medicine and science have neglected and misunderstood ME/CFS for so long that they really need to make up for their mistake by inspiring and supporting the most high-powered scientists available and funding a large group of experts in different fields to generate the best data and analysis possible.

The millions of suffering ME/CFS patients are owed an apology and a concerted urgent effort to find effective treatment.

**To support the project, go to [www.openmedicinefoundation.org/ways-of-giving/donate](http://www.openmedicinefoundation.org/ways-of-giving/donate) or contact us at [donate@openmedicinefoundation.org](mailto:donate@openmedicinefoundation.org).**