

**Testimony of Timothy Coetzee, Ph.D.
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Thank you Chairman Kucinich and Ranking Member Jordan. Thank you members of the Committee. I am honored to be invited to speak here today among many distinguished panelists and to represent patients who live with chronic neurological disease.

My name is Timothy Coetzee, and I am the President of Fast Forward, the venture philanthropy arm of the National Multiple Sclerosis Society. I am here today on behalf of the estimated 400,000 Americans and the more than 20,000 veterans who live with MS and are being treated by the Veterans Health Administration. The number of veterans affected by MS is yet more alarming given that the VA only treats about one-third of our veterans. Finally, I am also here on behalf of the researchers in the United States who are engaged in discovery and development of new treatments and ultimately a cure for MS.

Together, we ask you to help us advance MS research by providing resources and policies that support and expand collaboration between government, patient advocates, private foundations, pharmaceutical and biotech industry and academia.

No Cure for Multiple Sclerosis

Multiple sclerosis is a chronic, unpredictable, often-disabling disease of the central nervous system. It interrupts the flow of information from the brain to the body and stops people from moving. Every hour someone is newly diagnosed. MS is the most common neurological disease leading to disability in young adults. But despite several decades of research, the cause remains unclear, and there is no cure. The research must continue.

The symptoms of MS range from numbness and tingling to blindness and paralysis. MS causes loss of coordination and memory, extreme fatigue, emotional changes, and other physical symptoms. The progress, severity, and specific symptoms of MS in any one person cannot yet be predicted. These problems can be permanent, or they can come and go.

The National Multiple Sclerosis Society recommends treatment with one of the FDA-approved "disease-modifying" drugs to lessen the frequency and severity of attacks, and to help slow the progression of disability. But unfortunately, the cost is often financially devastating. The FDA approved drugs for MS cost more than \$30,000 a year, and these treatments continue over a lifetime.

Challenges to MS Drug Discovery

While we are grateful for the availability of seven FDA-approved disease modifying treatments and one FDA-approved symptom treatment, we need better and more cost-effective therapies. Finding these new therapies hinges on research and the collaborative efforts of all stakeholders.

Research discoveries can — and do — happen in a variety of ways. Some require years of careful shepherding, while some can seemingly happen overnight. Whether it's a molecule that could have potential as a new drug therapy, or a tool that can better track clinical trial results and make them move more quickly — each relies on crucial steps that must be taken in order to translate these discoveries into available treatments for people with MS.

Those many steps involve collaborators, commercial development resources, access to clinical trial participants, and obviously considerable financial resources. Progress in treatments for people with MS happens when the greatest numbers of researchers are working on the greatest volume of potential discoveries in the field of MS. We know all too well that promising research from the lab can often be applied to multiple diseases, and that researchers are forced to choose those with money, resources, and commercial potential. This means that in the past, promising therapies with potential in MS have never even made it into the commercial MS pipeline. There wasn't enough return on investment to make MS an attractive first choice.

Unfortunately this is true of many neurological diseases, not just MS.

Role of Patient Advocacy Organizations in Drug Discovery and Development

Fast Forward was created by the National Multiple Sclerosis Society specifically to drive investment into the commercial development of MS treatments and therapies — creating an investment that works for

everyone affected by MS. Like other patient organizations such as the Michael J. Fox Foundation for Parkinson's Research and the Alzheimer's Drug Discovery Foundation, we have made a commitment to ensure that potential new therapies have an opportunity to be developed for people with MS.

Too often, promising drug treatments languish because companies lack the funding or focus to conduct pivotal research to break through the barriers, move the compound through the development pipeline, and ultimately to the clinical trials needed to develop new MS therapies.

Fast Forward addresses this critical gap by providing seed money to academic groups and emerging biotechnology and pharmaceutical companies involved in drug research and development.

Fast Forward further fills the gap, often referred to as the 'Valley of Death' by creating a collaborative environment between scientists, clinicians, academic researchers and commercial visionaries. By creating these vital connections between the research, clinical trial and business communities, Fast Forward increases the focus on MS, further

speeding the process of bringing drugs to clinical trial. As a catalyst for collaboration, Fast Forward identifies emerging challenges, shapes research agendas and finds new opportunities for drug development in MS.

Sustaining Innovation in Neuroscience Research and Development

Fast Forward's story is not unique. Our peers at the Michael J. Fox Foundation for Parkinson's Research, the Alzheimer's Drug Discovery Foundation to name but two are engaged in similar important work to address neurological disease. Together we join with many other patient advocates calling for investments and policies to sustain innovation in neuroscience research and development.

In our view expanding and sustaining innovation in neuroscience research and development requires three critical elements.

First, we need to sustain a large and vibrant medical research community in the United States. Medical innovation requires a community of scientists and physicians actively engaged in pursuit of knowledge and understanding about basic biology as well as human disease. A vibrant research community generates a plethora of often

unconnected ideas which form the basis of medical innovations. Government funders such as the NIH, the Department of Defense, patient advocates, pharmaceutical companies, and other funders play a vital role in sustaining the neuroscience research community. It is vital that we continue and expand our commitment to fund basic and disease research funded by the NIH and programs at the Department of Defense, such as the Multiple Sclerosis Research Program (MSRP) within the Congressionally Directed Medical Research Programs (CDMRP). Without these investments, we will likely miss out on important innovations that could improve the lives of people with neurological disease.

Second, we must create an environment conducive to formation of fluid networks of scientists engaged in translational research. We know from our experiences at the National MS Society and Fast Forward that research and innovation happens faster when scientists, technologists, and translators, my term for people who take the basic lab discoveries and turn them into a drug, work together in networks across fields, institutions, and borders. Through these networks, ideas can be shared and linked together with other insights in order turn innovations into actual therapies. The key to success is that the

research networks are fluid and can adapt by adding new members, going in new directions based on results and so forth. Coordination by government agencies, private foundations and patient advocates is vital to ensuring that researchers are able to form these fluid innovation networks.

Third, government, private foundations, and patient advocates

must use their influence and financial resources to connect

innovators across sectors. At Fast Forward we serve this role by using

our financial resources and influence to connect our portfolio

companies with expert scientists in academic research centers. We

know first-hand that young companies are able to work smarter and

faster when they are working with established MS experts rather than

trying do the work on their own. All of the stakeholders must do more

of this in order to enhance and expand neuroscience research and

development.

In conclusion Mr. Chairman, the United States has a long history of

being a leader, indeed a driver, of neuroscience research and

development. Unfortunately, today we find ourselves in an

environment where economic challenges threaten our leadership in

this area. As patient advocates, we urge action to ensure that there is greater coordination among the stakeholders so that we can remain a leader in neuroscience research and development. Every day Americans receive the news that they have a neurological disease. These individuals do not have the luxury of time. They need our help and we can do that by creating a research environment conducive to discovery and development of breakthrough treatments that stop their disease and restore lost function.

Thank you for helping us move closer to a world free of MS, and thank you for your time.