



The Solve ME/CFS CHRONICLE

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FALL 2020

CEO Oved Amitay Ushers in the Next Chapter for Solve M.E.

By Ani Vahradyan, Solve M.E. Public Relations Coordinator

OVED AMITAY has always been interested in scientific discovery.

Long before his days of working at various biotechnology companies, Oved could be found distilling chemicals in a makeshift lab at his parents' home—the remnants of failed experiments still decorating the ceiling.

Oved now leads Solve M.E. as President and CEO, joining in June 2020 during a period of transition both within the organization, and across the country as the world grappled with the devastating coronavirus pandemic.

Oved pursued an education in pharmacy after receiving acceptances from both pharmacy and medical schools. He spent several years working at Cambridge Neuroscience—his first career in the pharmaceutical industry after completing his graduate studies in Pharmacology—before moving back to Israel and working for Genzyme, a biotechnology company dedicated to developing treatments for rare or specialized diseases.

It was at Genzyme that Oved found his passion for orphan diseases—diseases that are documented to affect fewer than 200,000 people—and for rare hereditary diseases in particular. Oved noted that ME/CFS has very similar disease characteristics to orphan diseases: lack of awareness, difficulty in diagnosing, shifting disease definition, insufficient funding for research and no industry interest. However, ME/CFS is not a rare disease, and it is estimated that there might be as many as

2.5 million people in the U.S. affected by it.

“When developing therapies for rare diseases, which often involve small populations, we work closely with the patient community,” Oved said. “I have been privileged to work with a number of patient advocacy groups over the years—something I’ve really cherished. These patient communities are all very different from one another; each has its own character.”

Oved is personally invested in advancing a cure for ME/CFS and helping individuals avoid what he called a “diagnostic odyssey” when it comes to understanding



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their illness. Oved recalled a close family member who exhibited symptoms of ME/CFS for many years before they were able to achieve a diagnosis.

His dedication to working with poorly understood diseases has led him to two important takeaways.

First, to understand the disease better, you must collect data broadly and systematically. This year, Solve M.E. launched the You + ME Biobank and Registry, a patient-led data-capturing program designed to connect patients and researchers. As COVID-19 curtails many research capabilities, this registry will help to advance understanding, develop diagnostic criteria, and ultimately find therapies for ME/CFS, Oved said.

Second, an invested patient community is essential. Patients often know more about their disease, and their experience with that disease, than anyone else, Oved explained. It is important to get community members involved in research and advocacy efforts, and keep them updated during outreach for funding and industry involvement.

“The community has incredible power,” Oved said.

As the reported numbers of “long haulers,” or people continuing to experience symptoms after contracting COVID-19, rise across the globe, Oved recognizes that this is a critical time for Solve M.E. He hopes that with the expertise Solve M.E. has about post-viral diseases and ME/CFS, they can serve as a resource to this emerging community and its pressing questions. Acknowledging the tremendous tragedy of the pandemic, Oved also said that this may be a period of transformation in post-viral disease research.

“For the first time in history, we may be in a position to follow patients who contract COVID-19 and go through their journey with them,” Oved said. “From a research and scientific perspective, we can begin to understand why some people do not recover, become ‘long haulers,’ or eventually reach an ME/CFS diagnosis.”

ME/CFS is a field-wide challenge, according to Oved. As such, he believes it’s an issue no single organization can solve alone. He sees Solve M.E.’s role as being an integrating force—a convener that can leverage its research and advocacy capabilities to this end. Oved said it is the responsibility of Solve M.E. and other organizations and agencies to amplify their complementary efforts to create the most powerful coalition possible. ■

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Oved and his wife, Dalia, at the summit of Mount Kilimanjaro, March 2020