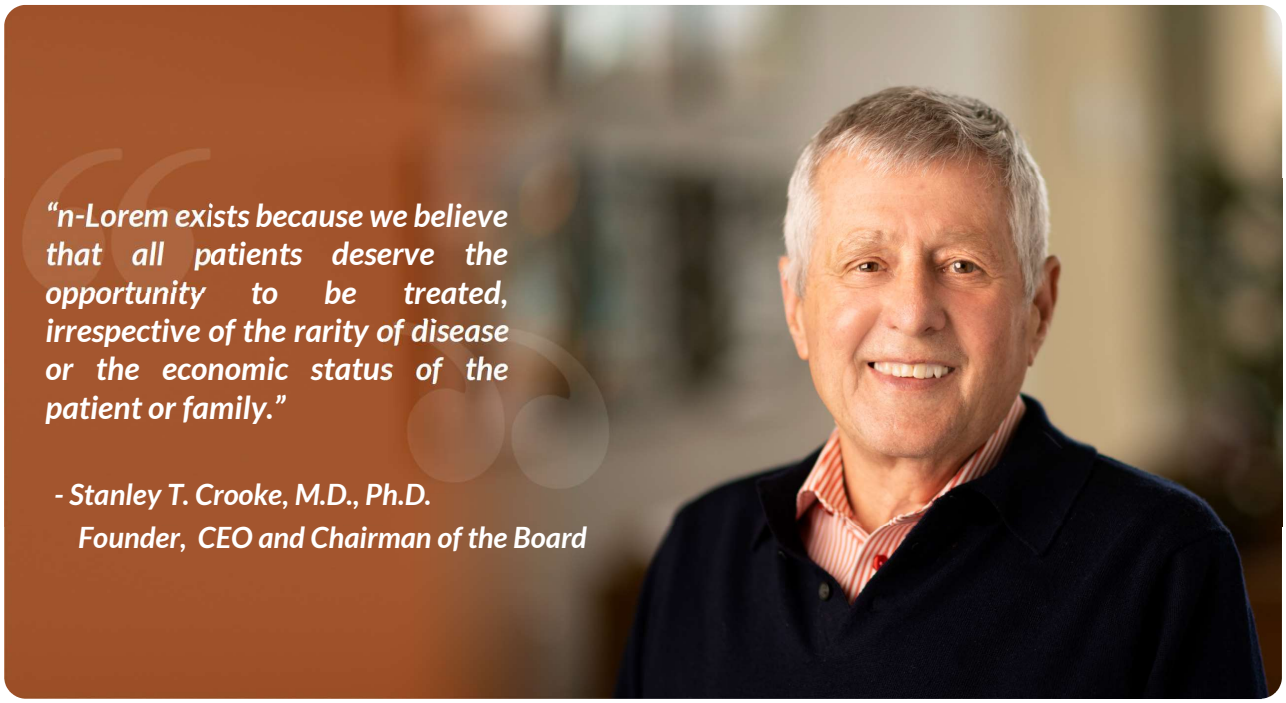

Dear supporters, partners, patients and parents,

As we move along into our sixth year, we have much to be proud of and much that we have learned, which we are now sharing. We also know that we have formidable challenges as we continue to grow to meet the ever-increasing demand and we are buffeted by the extraordinary political turmoil, as are so many institutions on which we all depend.

We have proven that what was impossible just a few years ago, can be done. Armed with ASO technology and the support of the FDA, we can initiate a new drug discovery program for each nano-rare patient and create a new personalized ASO medicine. We can do that repeatedly and we can provide these medicines to needy patients for free, for life — proving that "an impossible" non-profit model can work — and work well. We have proven that if you really understand ASO technology and industrialize the process as we have done, experimental ASOs can be administered to many patients with excellent safety and tolerability.

Most importantly, we have shown extraordinary benefit in 11 of the 12 patients who have been treated long enough to evaluate for benefit. We have shown benefit in patients with CNS, kidney, and eye diseases, and we have shown very long-lasting, profound benefit. We have proven that even patients suffering from the most advanced diseases can experience profound benefit. And we have shown that patients with profound developmental delays can recover long lost abilities or even abilities they never had. For the first time, we have proven that ASOs can dramatically reduce neuropathic pain and improve dysfunctions of the autonomic nervous system, the nervous system the controls heart rate, blood pressure, respiration, and the GI and GU tracts.

n-lorem FOUNDATION

Today we have received well over 350 applications and accepted >180 nano-rare patients for treatment and filed >30 INDs.

> 30 Patients Started Treatment

We have changed the lives of many patients and families and provided realistic hope to many.

We have built a world-class organization capable of filing more than 20 INDs a year. We have created systems and extramural review committees that help assure that we make the highest quality risk-benefit decisions for each of our patients. We have established a network of outstanding treatment centers with which we collaborate across America. We have proven that the novel approach we have taken to clinical trials is providing high-quality data and we are learning how to optimally use caregiver assessments. Finally, we have shared what we are learning through more than 10 scientific publications.

We have rapidly grown to meet the extraordinary demand. We received more than 350 Applications for Treatment, accepted more than 180 patients, filed more than 30 INDs, and are treating mor than 30 patients. No organization has accomplished anything within 10 times of what we have done.

We have not accomplished all this ourselves. We have benefited from many industry partners, many generous donors, and many volunteers. We thank all of you for your support.

As I look to the future, I am confident when I say that we have overcome every "impossible" barrier, save one. Only continuing to raise the increasing funding needed stands in the way of treating thousands of patients around the world. As daunting as that challenge, I am buoyed by our success and confident that with your support, we will overcome the remaining challenge.

I am also proud to share that we will host our third annual nano-rare patient colloquium, Oct. 20 & 21 in Cambridge MA, where we will provide more details on what we are learning and what we can do together. I invite you to come to this important meeting. More details and free registration can be found on our website (www.nlorem.org).

Sincerely,

Stanley T. Crooke, M.D., Ph.D.