



October 24, 2021

Dear Dr. Collins,

I read of your retirement as Director of NIH with great sadness. I pass along the same sentiment from our Spokesperson Kathy Bates. We trusted your dedication and passion. Given recent momentum in addressing the suffering of the 10 million Americans with lymphedema, it is hard to not feel our cause will suffer a set-back in the transition to a new Director. That said, we just received a three-year CDC Lymphedema Awareness Campaign grant, which is a sign of change.

Dr. Collins, thank you for including me in the Zoom meetings related to the ARPA-H. This was generous of you and gave such hope to the community that their plight was gaining recognition. I understood that you may have sought a more general report than the one I presented, however, there is so much that we can be doing now, rather than relying on the passage of ARPA-H. Now, I hear that the ARPA-H language was the first thing removed from the upcoming Appropriations bill as Congress ran into trouble securing the necessary support for passage.

Dr. Collins, I know you have received dozens of letters from our patients describing their suffering, lack of treatment options, and sense of abandonment. You have heard from those contemplating suicide because of the impact of lymphedema on their lives. You have read of their hopelessness given the historically low priority given to lymphatic research. They grieve because there are no drugs to treat them, while new surgeries that offer promise need considerable research before being insurable and readily available.

I am asking you to consider fast-tracking the lymphatic research field. Last year, Congress requested that NIH establish a National Commission to study the need for lymphatic research. I realize that you questioned the need for this Commission as you reflected on the Trans-NIH Lymphatics Committee. However, the Trans-NIH committee is far from able to create the change we seek. LE&RN helped establish this committee and has been at every meeting. With brief meetings once or twice a year, this simply isn't a reactive enough forum of key decision-makers empowered to deliver change and to thoroughly analyze the need for lymphatic research throughout NIH. The House version of the FY2022 Appropriation bill directs NIH to establish the National Lymphatic Commission. I implore you to make this part of your legacy. Rather than wait for the bill to pass next year and have your successor be the one to act, I ask that you take on the role of champion to this community by establishing the Commission during your tenure. And with fear of pushing too hard, any announcement of additional NIH funding for lymphatic research would be met with cheers from this community.

Thank you for your mighty service throughout this past decade, Dr. Collins. Your legacy was already secured before you then had to see us through the pandemic of the century.

I spoke with Kathy Bates recently who shared my sentiments and asked that I thank you for all you do. I hope you will consider one more opportunity you have to burnish your legacy and raise the hopes of the millions of Americans suffering from lymphatic diseases.

Sincerely,

William Repicci
President & CEO

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