## **DEPARTMENT OF HEALTH & HUMAN SERVICES**



**Public Health Service** 

National Institutes of Health National Heart, Lung, and Blood Institute Bethesda, Maryland 20892

March 18, 2022

William Repicci
President & CEO, Lymphatics Education
& Research Network
154 West 14<sup>th</sup> Street, 2<sup>nd</sup> Floor
New York, New York. 10011

Dear Mr. Repicci:

Thank you for forwarding the Lymphatic Education & Research Network (LE&RN) Open Letter calling for a National Lymphatics Commission to NHLBI Director Dr. Gary H. Gibbons earlier this year. The matter was brought up again and addressed by Dr. Gibbons at the annual NHLBI Constituency Group meeting on January 19, 2022. I wish to provide a more thorough response as a follow up to the request and the conversation and wish to start by saying that NIH is supportive of the community's request for a more open national body to advance research in lymphatics disease.

As you are aware from your connection with the NHLBI's scientific leadership team for the Institute's lymphatics research portfolio, led by Drs. Zorina Galis and Selen Catania, much activity and commitment are underway to advance research in this area. We feel the progresses to date yield a fertile foundation for evolving a new structure. As a reminder, the recent activities of these leaders and the longstanding commitment of the Trans-NIH Lymphatic Coordinating Committee (TNLCC) includes, but is not limited to:

## Focus on Tracking Progress of the Science

The NHLBI co-sponsored a workshop on Nov. 4, 2021 with the Boston Lymphatics Symposium, <u>"Yet to be Charted: Mapping the Lymphatics System Across the Body Scales</u> <u>and Expertise Domains."</u> You may find <u>a summary</u> from the workshop on the NHLBI website.

As you are likely aware, that workshop was instrumental in:

- providing an up-to-date review of the state-of-the-science by clinical researchers that focused on the need to fill gaps in knowledge to advance patient care.
- leading the call to bring together the lymphatic research community for an in-depth understanding of lymphatic vasculature, function, and lymphatic disease development -- through a comprehensive mapping of the lymphatics system across the entire body. This foundational knowledge will catalyze efforts to provide diagnostic and therapeutic tools for clinicians to treat patients with lymphatic diseases.
- presenting existing NIH resources seeking to collaborate with the lymphatic experts
- emphasizing available funding opportunities in advancing mapping of the lymphatic system. See <u>RFA-RM-21-026</u>: "*NIH expects and will prioritize supporting Centers that will complete building an atlas for the following organs: kidney, colon, spleen, thymus, lungs, bladder, skin, heart, female reproductive organs, eyes, bone and bone marrow, pancreas, and liver. In addition, the NIH expects to support at least one Center focused on mapping the vasculature, lymphatic, and peripheral nervous system in multiple organs.*

## Mapping the Lymphatics

The trans-NIH Human BioMolecular Atlas Program (<u>HuBMAP</u>) funded through the NIH Common Fund and co-led by NHLBI, NIBIB and NIDDK, has made mapping the lymphatic system a priority.

A major Tissue Mapping Center dedicated to mapping the lymphatic system: "<u>A 3D</u> <u>Tissue Map of the Human Lymphatic System</u>" was funded in 2018. The new call for applications <u>RFA-RM-21-026</u>, released in 2021, called for the completing of the lymphatic system. The RFA was promoted via workshops and awards are expected in summer 2022.

- 1. Open data and knowledge management resources supported through the NIH HuBMAP infrastructure were introduced and offered to the lymphatic research community in a series of calls to action and meetings organized in 2021. It was also a main goal of the "Yet to be Charted" Workshop.
- 2. Progress was made toward a modern version of the lymphatic vasculature map by Drs. Singhal and Itkin in collaboration with the HuBMAP Mapping Center.

## Homing in on NIH Investments in Lymphatics Research

As you are aware, lymphatics research is conducted across several Institutes of the NIH. To ensure that interested scientists, clinicians, and patients will be able to explore NIH's full portfolio in lymphatics research, the TNLCC has worked with the Office of the NIH Director to develop a mechanism to analyze and make transparent NIH investments in lymphatics research through <u>NIH's Research</u>, <u>Condition</u>, and <u>Disease Categories (RCDC)</u> system. This effort will result in a public-facing set of RCDC categories that will allow interested parties to view a list of funded lymphatic research projects by fiscal year, and to access the details of each project, including published results and patents, through the <u>NIH Research Portfolio</u> <u>Online Reporting Tool (RePORT)</u>. We expect this new RCDC category to be operational in 2022.

With these exciting advances, we welcome the opportunity to collaborate with LE&RN, the lymphatics research community, and those affected by lymphatics diseases in building a blueprint to further define a structure aligning with the concept of a national commission for lymphatics research. Through a planning process that leverages an initial baseline analysis of the new lymphatic RCDC categories and the most recent summaries on the state of lymphatics science, we can evolve a collective approach toward setting a mission, strategic objectives, and structural format for a commission that engages researchers, patients, clinicians, and other stakeholders to advance lymphatics research to gain new insights and deliver relief to the thousands of Americans who struggle daily with lymphatic disease. Also, it is important to understand is that we are responsible for ensuring that any new structure complies with the Federal Advisory Committee Act (FACA) of 1972 (PL 92-463).

We share a mutual goal to advance basic, translational, and clinical research that may lead to better ways to diagnose, treat, and prevent lymphedema and other lymphatic diseases.

Thank you for your patience and your leadership. We look forward to collaborating with LE&RN and others in the months ahead.

Sincerely,

Lenora Johnson

Lenora E. Johnson, DrPH, MPH, Director Office of Science Policy, Engagement, Education, and Communications National Heart, Lung, and Blood Institute, National Institutes of Health