

# **UPDATE TO DONORS:** ME/CFS and Long Covid

January 2023



## THANK YOU

On behalf of the 25,000 kiwis who suffer from Myalgic Encephalomyelitis/Chronic fatigue syndrome (ME/CFS), and the rising tide of those diagnosed with Long Covid, thank you for your generous support of the Brooks Lab and our research on post-viral illnesses.

This year has seen a significant increase in the attention, public concern, and enormous economic and human cost of post-viral illnesses with an estimated 1 in 10 people experiencing Long Covid following COVID-19. Unfortunately, this has not translated to an increase in the research and funding to address this increasing and urgent need.

Thus, I am grateful to be the recipient of such generous community support of our research into the identification of biomarkers of these illnesses so that diagnostic tools and treatment options can be developed. Most tangibly your gifts have enabled us to contract two part-time casual technicians and a fulltime Research Assistant in the past six months, significantly increasing the speed of our research. However, to keep momentum, we hope to be able to continue supporting our team to advance this important research.

I am also excited to share that a group of researchers and patients have established 'Post-Viral Research Aotearoa' to help raise awareness, funding support, and disseminate research updates on our quest to shed light on these poorly understood diseases and work towards diagnostic tools and treatments. A new website for this group has just been launched and we invite you to take a look and share with your networks: <a href="https://www.pvra.nz">www.pvra.nz</a>

Thank you for your support and for changing the future of those with ME/CFS and Long Covid.

With best wishes,

Dr Anna Brooks

Brooks Lab and Director of Auckland Cytometry

#### **BACKGROUND**

There is an urgent need to identify the underlying biomedical mechanisms associated with Long Covid and ME/CFS so that diagnostic tools, and importantly treatment options, can be developed to improve outcomes for all those living with post-viral conditions.

Why does the immune system malfunction? Already research is beginning to reveal the similarities between persisting symptoms following COVID-19 illness and ME/CFS. Immune dysfunction is likely to be central to or tightly associated with most if not all the hypothesised causes of Long Covid (e.g. autoimmunity, poor/dysfunctional immunity, viral persistence with or without reactivation of underlying latent viruses, vascular damage (blood vessels) and disrupted coagulation (blood clotting) systems.

Mounting evidence suggests that many with Long Covid may have experienced a poor or dysfunctional immune response which warrants deeper investigation. Therefore, characterising the immune response in those that recover versus those that progress to the post-viral condition may be critical to understanding the associated immune dysfunction and the relationship to ME/CFS.

Our research is focused on unpacking the immune dysfunction experienced by those with Long Covid with the aim of understanding the relationship to ME/CFS – the more common but still poorly understood post-viral condition. Diagnostic tests and treatment options for both these conditions are sorely needed.



#### RESEARCH ACTIVITY

Your support has helped us with the launch of the study and establishment of a suite of specialised immune tests for those with Long Covid and ME/CFS. This will not only benefit New Zealanders – this study will have a significant influence internationally too.

One key development that occurred in late 2022 was the extension of the study to include people with ME/CFS, as well as known and probable (undiagnosed) Long Covid. This was incredibly important given the similarities between these illnesses and the urgent need to include previously neglected patient groups in this important work.



One of the goals over the next year is to assess utility of at-home blood and saliva sampling kits, particularly given many living with these illnesses are house-bound or find attending appointments difficult. We hope to at least gather preliminary data to better understand the logistics and utility of this approach alongside traditional blood draw sampling methods.

In collaboration with the team at Auckland Cytometry, our team have been working on developing a number of advanced immune cell profiling tools (high dimensional spectral flow cytometry panels) which will enable us to perform complex analyses to determine

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whether a 'signature' of immune dysfunction can be uncovered. The team have also been collaborating with a NZ-based Research and Development company, Pictor Ltd, to better understand COVID-19 antibody responses in people with Long Covid.

The team are only in the early stages of developing various immune tests, and still have a lot of work to do, but are excited about the year ahead. Other areas the team will be focussing on include investigating the link between viral reactivation (latent viruses), mitochondrial function and immune dysfunction in these patient groups.

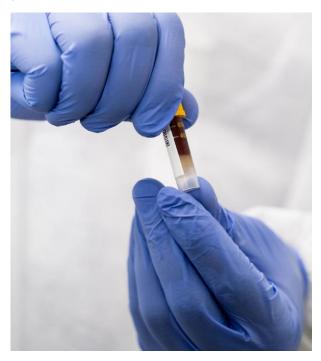
As we head into 2023, the Brooks lab are excited to welcome a number of post-graduate students. The first to join the lab is a MSc student visiting from the University of Strasbourg in France who will undertake an internship to help advance these studies. Three other students (2 x PhD and 1 MSc) are also on track to start in the coming months.

Details about the team members and their projects will be posted on the <a href="www.pvra.nz">www.pvra.nz</a> study website in due course. Make sure to check in regularly for updates. Details on how to join the study can also be found on the site.

### **FUTURE IMPACT**

The COVID-19 pandemic has brought long overdue attention to the urgent need to better understand these incredibly debilitating illnesses which at least brings us hope that effective treatments can soon be developed.

There is no single test and no cure for ME/CFS and Long Covid. With your support, we're closer than ever to developing these, thank you!



If you would like to know more about supporting research on ME/CFS and Long Covid, contact:

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