Dr. Robert McMaster VP Research, Vancouver Coastal Health Executive Director, VCH Research Institute Room 3665, 910 West 10th Avenue Vancouver, BC V5Z 1M9 604.875.5641

Mavis Dixon

Community Advisor and volunteer to CeMCOR

Director of Projects and Engagement for Ayogo Health Inc.

Dear Dr. McMaster

I am writing to express my strongest support for CeMCOR. I urge the VCHRI to fund CeMCOR as a VCHRI Program. It is astounding to me that this frugal little centre has contributed 17% of almost \$2M it has received in Tricouncil funding to the VCHRI. While CeMCOR contributed more than \$300,000 to VCHRI, the amount VCHRI committed to CeMCOR from 2002-2016 amounts to just \$60,000. Worse, I understand that CeMCOR's very frugality is the reason for VCHRI's decision to deny it program standing, because CeMCOR fails to meet a \$1 million threshold for infrastructure funding.

When I joined CeMCOR as a community advisor, I was very surprised by the low level of operating support the centre received. As someone with decades of experience in the non-profit and health sector, I could see CeMCOR was producing a significant body of research and the public impact of an organization 10 times CeMCOR's size!

Dr. Prior and Dr. Shirin Kalyan have helped countless women better understand how our hormones are in continuous interaction with our environment, diet, exercise and social stresses, and how we evolve naturally, and at times we need help with what can become excruciating difficulties. CeMCOR provides evidence-informed answers on subjects from contraception to bone health, fibroids to PCOS/anovulatory disturbance, conception to aging well. These are topics that touch every woman. Each year, over a million visitors turn to CemCOR for this critical, non-commercial health information, because it is relatable and useful. Women can't get these specialized answers from their general practitioners.

While I was never a patient of Dr. Prior, I have met many grateful women who were. Her email inbox is full of notes of thanks, because she still offers personalized advice to this day. As an endocrinologist, she has an unusual, nuanced perspective. While leading serious research she also takes time to write accessible, patient narratives, and has published award-winning books that express science through the lives of peri-menopausal fictional women who are facing true-to-life scenarios. The proceeds from these wonderful books go to fund CeMCOR. They are now being picked up by international health organizations and translated, most recently into Portuguese.

CeMCOR's research has challenged conventional thought. CeMCOR has even self-funded rigorous RCTs, with Dr. Prior subsidizing research by donating back her own professor emeritus salary. Through this passionate commitment to research, CeMCOR has been able to uncover and challenge "given truths". For example by showing women often have *higher*

than expected estrogen levels during peri-menopause. This research was a complete paradigm shift at a time when doctors or pharmaceutical companies were counterproductively promoting estrogen replacement to perimenopausal women.

I worry that without program support from the VHCRI, CeMCOR will not be able to secure an adequate successor to Dr. Prior. I ask that the VCHRI invest in CeMCOR and fund it as a program. Alternatively, we all risk losing an invaluable resource to women's research. CeMCOR.ubc.ca provides a completely unique, non-commercial source of information on women's health, hormonal change and whole-body impacts, from adolescence through midlife to menopause.

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Mavis Dixon

April 18, 2017

Dr. Robert McMaster

VP Research, Vancouver Coastal Health Executive Director, VCH Research Institute Room 3665, 910 West 10th Avenue Vancouver, BC V5Z 1M9 robert.mcmaster@vch.ca

Dear Dr. McMaster,

I am writing to you today regarding the importance of finding a way to embed the work done by Dr. Jerilynn Prior and CeMCOR in the VCH Research Institute. Dr. Prior's commitment to sharing medical science in an accessible way has helped me to recover a sense of "owning" my own health. I have benefitted from access to cemcor.ca, and I have been able to help others by referring them to specific information on the site.

Approximately 8 years ago, I was in need of help with hormonal changes, help that my doctor and my gynecologist were unable to provide. I floundered for a couple of years with health issues that could not be addressed, but which were affecting my ability to work, parent, and stay active. I am a Communication Consultant and I put my many years of experience to use by trying to find with many years of research experience that I put to use during that time, attempting to find information to help me with the changes that were occurring in my body. In 2011 I was fortunate to discover Dr. Prior and the CeMCOR website. When I first found the website, I couldn't believe my eyes. Here were *scientific*, *evidence-based articles* describing my symptoms WITH descriptive instructions and *reliable* remedies that I could employ. I no longer felt like "it was all in my head" and took copies of the documents to discuss with my doctor so that she could prescribe what I needed.

What I had not realized was that, at that time, was that I was entering into perimenopause – a word I had learned, used during an American PBS women's health program – and I was to find that cemcor.ca would continue to assist me. Having done an array of investigations online, including the use of the PubMed database, I found that Dr. Prior's CeMCOR website was not only scientific, evidence-based information; it was easily understandable. Because the information is accessible on CeMCOR, I am more comfortable referring friends and family to the site than I am referring them to PubMed. While the PubMed information is undeniably valuable, it is not always accessible by people without medical backgrounds and determining which papers yield reliable conclusions does take some understanding of scientific method.

I believe women in my generation are in a position of responsibility to the women who will come after us; people like my daughter. If we do not work hard to make sure that <u>reliable</u> research in the areas of women's reproductive health continue to be recognized, researched, discussed, and publicly available, we are leaving women to further distress and isolation as they seek answers to the those life changes that are only relevant to women.

Unfortunately, I have learned that Dr. Prior is considering retirement. Will you consider working through VCHRI and UBC to guarantee that CeMCOR continues to carry on the work of Dr. Prior, once she actually retires? CeMCOR is a trusted institution. In 2013, 49.6% of the world's population was female, that is over 3.5 billion women who *need* the reproductive health information that Dr. Prior recognizes as being central to the long-term health of women.

Dr. McMaster, finding reliable and accessible information about women's reproductive health through the years <u>is very difficult</u>, until you access the CeMCOR website – which is now helping my daughter. Please, do everything in your power to ensure this resource not only continues to exist, but becomes a strong program that researches and addresses women's reproductive health issues, and communicates openly about real-life solutions that women all over the world can employ. While you may have particular methods of operation that I am not privy to, you do have women in your life and I can guarantee that many of them have not openly expressed their need for access to this kind of information. I continue to encounter women who are embarrassed to discuss their reproductive health – our societies are still struggling to recognize that women's reproductive health is a real world experience. It will be a very innovative decision for VCHRI to choose to cut the path for women's reproductive health by making CeMCOR part of the VCH Research Institution, ensuring enduring research and access.

With gratitude,

Sue Seward

Dr. Robert McMaster,

VP Research, Vancouver Coastal Health Research Institute

Executive Director, VCH Research Institute

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cc: Faydra.Aldridge@vch.ca

Dear Dr. McMaster:

Re: Rejection of the Centre for Menstrual Cycle and Ovulation Research as a Vancouver Coastal Health Research Institute Program

I am writing as a woman helped by CeMCOR to request that VCHRI reverse the rejection of CeMCOR as a Program. I am a female who has suffered with hormonal issues for close to 20 years. I have been seen by a number of specialists who have been able to offer me some help, but have never rendered me free of symptoms...hot flashes at night, causing major sleep deprivation and all the fun things in life that go with that! Since I have been on HRT for many years I really want to get off of them. I had been unsuccessful with the approach that the specialist I see offered me. A year ago I came across an article by Dr Prior and since then have read all of her/CeMCORs work. I have been in correspondence with Dr Prior via email and she has been most helpful. I am currently using her protocol to wean myself of HRT. As a female who has suffered greatly for many years, (as well as a nurse), I think that the work that is being done by Dr Prior/CeMCOR is extremely valuable and so needed by all women. I often wonder if this were a male problem, if there would be more attention/resources given to this area of research.

From my perspective this work needs to continue and if anything be expanded, not rejected!! The website alone contains so much valuable information on it. I have referred many of my female (and male) friends to the site, as well as patients that are having hormonal issues. The research is innovative, practical and excellent science that **needs** to continue. To be able to keep this service going, CeMCOR needs VCHRI support.

There is solid evidence that CeMCOR, despite its small size and infrastructure of \$50-75,000/year is very productive in creating innovative and practical science and excellent at sharing of this new knowledge. There is also objective evidence of the knowledge translation effectiveness of CeMCOR's website that receives >3,500-7,000 page views/day from >180 countries

It is not right that this women's **health-**focused research should be unsupported while many disease-focused and general or men's health related programs and centres are provided funding.

It also doesn't seem right that federal (taxpayer) money from the Treasury to support infrastructure in research be earned by CeMCOR but allocated instead to other entities given that CeMCOR is too poor to meet the VCHRI criteria for having a million dollars in infrastructure money. Specifically, a portion

(approximately \$150,000) of what CeMCOR has earned from TriCouncil grants over the last 15 years has gone to VCHRI. Over the same time period CeMCOR has received \$59,729 in support from VCHRI.

I am looking forward to your constructive response to these concerns and am hoping that my letter may play a small role in affecting a positive outcome for this crucial research program.

Sincerely,

Elsie Konopad RN, MN