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Dear Members and Friends,

I have some very exciting news, and want to ask for your help in a new undertaking.

Last year, thanks to the efforts of our hard working project steering committee, we submitted a grant proposal to Ontario's Trillium Foundation. It requested funds for a study to, "improve quality of care and support" for people in this province suffering from ME-CFS, ES-MCS and FM. You may already have heard that we were successful in obtaining the grant. Did you know that this is the first time a significant sum has been made available through a government source for such investigation in nearly twenty years?

Over the winter and early spring months, our Steering Committee and board developed a request for proposal (RFP), designed to find the best consultants to carry out this project. In late May we made our selection (Canary Consultants), and we are now underway.

Our project has two major objectives:

First objective is to identify the major needs our people have and the major 'gaps in service' in terms of those needs, and second to propose solutions for filling those gaps. Our findings and recommendations are meant to be of use to key decision makers in the Ministry of Health and Long Term Care and in the service delivery part of our health care system. Meeting this objective will form the bulk of the study. This work has six major components you may be curious about:

1. A survey of clinical and academic perspectives: Bringing together the most relevant and up to date clinical and academic findings and the best and most promising practices with respect to the conditions we're dealing with.
2. Identifying patient and caregiver needs: this includes approximately 30 in-depth patient interviews, 4 focus groups and the design of a survey 'instrument' – a questionnaire – to be used eventually in a survey study large enough to yield 500 responses.
3. Issues and priorities for other health care experts, potential partners and health system stakeholders: Here we will be researching and connecting with key potential partners and front-line service providers: the MOHLTC, local health integration networks (LHINS), community health centres (CHCs) at the central and local levels, the OHA, and so forth.

4. Developing and proposing a model of care: from all aspects of our research, and keeping in mind the Ontario governments major policy framework on chronic disease management, we will then propose a model of care – meaning which actual elements of medical care, home and other social supports are needed for our groups.

5. Delivery mechanisms: In this section we will discuss what types of delivery mechanisms are needed to put this model of care in place.

6. How to bring it all together in Ontario – an exciting new proposal for ‘on the ground implementation’ for Ontario.

The second part of this project is geared to assist MEAO to mature organizationally so it can take up a stronger role as a patient organization within a healthcare landscape that is changing for the better for our communities.

I am writing to you today to let you know of these exciting new developments, and indeed to ask for your help. *Anyone who would like to be involved in the planned patient research – individual interviews in August and early September and focus group discussions in mid to late September – we would love to hear from you by August 30th if possible.*

We want as many people as possible to contribute, not just MEAO members. Please forward this letter on and encourage anyone who suffers from; one or more of the three illnesses; was diagnosed by an MD and who lives in Ontario to participate and sign up for an individual interview or focus group discussion.

In addition to forwarding this letter, please print up the attached flyer and post it wherever participants might be found (e.g.) doctors’ offices, at your local health food store, at your chiropractor or naturopath and so forth.

Please send us an email at qocproject@meao.ca or leave a message on our help line at 416-222-8820 or 1-877-632-6682 and MEAO’s project coordinator, Kristine Peruzzi, will contact you. The richer and more comprehensive our research is, the better our proposals to decision-makers can be. Please get in touch!

We will keep you posted of breaking news as the project unfolds.

Sincerely,



Keith Deviney
President, MEAO