



CareNow Ontario is an organization representing and supporting the medical conditions of **Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)**, **Fibromyalgia (FM)** and **Environmental Sensitivities/Multiple Chemical Sensitivity (ES/MCS)**

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**DRAFT**

**MINUTES – ANNUAL GENERAL MEETING of  
CareNow Ontario Thursday, November 28<sup>th</sup>, 2024  
1:00 p.m. – 3:00 p.m.  
Held through Zoom Video Conferencing**

**Call to Order: Announce Quorum**

The meeting was called to order at 1:05 p.m.  
Chair: Keith Deviney  
Moderator: Adrianna Tetley, Treasurer

Quorum Achieved: 18 members participated (9 by Zoom/phone, and 9 Proxies).  
See list of participating Voting Members in Appendix A.

Housekeeping

- Adrianna Tetley presented the rules for the meeting.
- Meeting was recorded with the consensus of the attendees. All members were put on mute.
- President only votes if there is a tie but will vote for the proxies she holds.

**1. Approval of Agenda:**

The agenda was presented to the members for approval.

**Motion:**

**Be it resolved** that the Agenda now before this meeting, held November 28<sup>th</sup>, 2024 be approved as presented.

Moved by: John Doherty  
Seconded by: Laurie Menard

17 in Favour - Motion Carried

**2. Special Presentation: Advancing Accessibility and Human Rights for people living with Multiple Chemical Sensitivities across Canada.**

Rohini Peris, President, L'association pour la santé environnementale du Québec - Environmental Health Association of Quebec (ASEQ-EHAQ) presented on Advancing Accessibility and Human Rights for people living with Multiple Chemical Sensitivities across Canada. See separate ppt for further information.

**Question #1 (addressed to Rohini):**

How do you see trying to capitalize on that growing awareness and understanding to advance the cause?

**Response (by Rohini):**

- currently putting down all the minute details of what has been achieved.
- building up phase two in the 10 month extension that the government has approved.

**Question #2 (addressed to Rohini):**

Which federal government agencies funded your activity and how did you raise the money? How did you convince the federal government to fund what you did?

**Response (by Rohini):**

- This group is a collection of many partners and great support of Dr. John Malot and Dr. Lynn Marshall.
- Before this project, worked with the government on different panels for universal accessibility, where we looked at everything that needs to change, for inclusion of MCS.
- included other chronic conditions.

**Question #3 (addressed to Rohini):**

Which division in the government?

**Response (by Rohini):**

- Disability

**Question #4 (addressed to Rohini):**

How do you find the grants?

**Response (by Rohini):**

- Search the internet.

**Question #5 (addressed to Rohini):**

Quebec came out with a report that said MCS was more psychological than biological. How are you taking this project with the biological vs psychological debate? How are you positioning this project? Have you had any barriers in decision and fund makers in that area?

**Response (by Rohini):**

- Don't experience any barriers, because we don't talk about the psychological. We talk about the hardship and the pain and suffering that people are experiencing.
- Going to the National Assembly in May next year with a petition. That petition will be supported by the opposition parties and a number of groups in Quebec in asking for scent-free healthcare in Quebec
- The submission in that petition it's not just MCS, it's all the other conditions too.

**Question #6 (addressed to Rohini):**

Can you speak more about your International Conference in May?

**Response (by Rohini):**

- Two day conference May 1<sup>st</sup> and 2<sup>nd</sup> 2025
- The aim of the conference is to give support to the researchers, acknowledgement and thanking them for their work.

Rohini Peris has invited CareNow Ontario to sponsor the event. It will be brought to the board for consideration.

CareNow Ontario acknowledges all of the vital work ASEQ is doing and thanks Rohini Peris for the highly educational presentation.

### **3. Approval of Draft AGM Minutes of November 1<sup>st</sup>, 2023:**

#### **Motion:**

**Be it resolved** that the Minutes of CareNow Ontario Annual General Meeting of November 1<sup>st</sup>, 2023 be approved with the following amendments:

Pg. 1 item 2: be amended from “as present” to “as presented”

Pg. 3 item 5.1(2): add reference “with the assistance of consultant Bill Manson, formerly with the Toronto Central LHIN”

Pg. 6: Add “Directors Report was a verbal report”. Delete “will be attached with the AGM minutes”.

Member Eleanor Johnston submitted amendments in advance.

Moved by: John Doherty  
Seconded by: Laurie Menard

16 in Favour, 1 Abstained - Motion Carried

### **4. Update on Advocacy and Government Relations Re: Action Plan Report for the Task Force on Environmental Health:**

#### **1. Update of Action Plan on Task Force Report on Environmental Health:**

CareNow Ontario’s core business is to get the report released and get the business case implemented. Despite regular and ongoing advocacy to Minister's office and the Ministry of Health there has been no response to the overall progress of the Task Force Report.

CareNow Ontario stays firm on our three Calls to Action to the Government and will reinstate them immediately after the next election and the appointment of a new Minister of Health.

The **three Calls to Action** submitted to the Ontario Ministry of Health;

#### **Calls to Action to Government of Ontario:**

1. To implement and fund the recommendations in the Business case for a Centre of Excellence In Toronto, regional MCS safe clinics and local, specifically trained primary care, submitted in 2013.
2. To immediately release **Laying the Groundwork**, an action plan developed by Dr. Brian Schwartz, former Vice President, Public Health Ontario, with the assistance of consultant Bill Manson, formerly with the Toronto Central LHIN, submitted to the Minister of Health in July 2022
3. immediately fund the development of case definitions and clinical guidelines for best practices and clinical pathways; fund development of clinical curriculum and require Ontario universities to incorporate this curriculum along with research projects into medical schools and public health schools.

## **2. Action Plan Release: Freedom of Information Request:**

In 2022, NDP Health Critic, France Gelinias filed a Freedom Of Information (FOI) request to release the implementation report. CareNow Ontario received a redacted report that only left the table of contents and the name of the people consulted.

NDP has gone through three levels of appeals with no success.

The NDP has run out of options to appeal so this process has now been deemed closed unsuccessfully, with no further information released.

*Possible Next Steps:*

- Meet with the NDP, Green Party and the Liberals prior to the election to see if we can get their support.
- Election is expected in spring 2025.

## **3. CEP Primary Care Tool:**

The Ministry of Health provides CEP with annual funding to create resources for primary care physicians. This work is funded through the Primary Care branch.

CareNow Ontario is not clear on who in the Ministry of Health advocated that the CEP Tool for ME, FM, POTs and MCS be on the list for development in 2023-24. We are grateful for the development of the tools, but it would be useful to identify the person in order to determine who to contact.

Not clear if this tool was a result of the 'unreleased' implementation plan. Currently no evidence of other work being done.

CareNow Ontario has been clear with Ministry of Health and CEP, that while we cautiously support the development of these tools, it is by NO MEANS sufficient to meet the vision of the Business case for the Centre of Excellence.

Denise Magi, on behalf of CareNow Ontario was a member of the Topic Expert Group (TEG) and spent many hours on the development of these tools.

In late summer 2024, three tools were released: FM, ME/CFS and POTS and posted on the CEP website. These tools will be very helpful for physicians and nurse practitioners with patients with these conditions.

As of today, the tools have been downloaded 3515 times.

At the same time, one very damaging and misleading paragraph was put on the CEP website re MCS.

On May 15<sup>th</sup> Awareness Day, CareNow Ontario held a webinar to share the positive news of the three developed tools and to present the problems with the one MCS paragraph.

CareNow Ontario immediately sent a letter to the Minister of Health to request that the paragraph be removed.

France Gelinias, NDP personally presented the letter to the Minister and spoke on behalf of CareNow Ontario.

Two weeks later, the paragraph was removed.

Special thanks to MPP France Gelinás for her intervention, since the Minister was not aware of the letter or the paragraph.

Despite the disappointment and the unjust decision to withdraw the tool development for MCS, the development of the tools for ME/CFS, FM and POTS was a positive achievement, because up until now, primary care providers had no such tools for these illnesses.

#### **4. Primary Care Tool for MCS - Sessional Paper Q 222 by F. Gelinás - May 2024**

MPP France Gelinás had written to the Minister on May 27<sup>th</sup>, 2024 with the following question (Sessional Paper Q 222):

***Would the Minister of Health please indicate when her Ministry will develop a multiple chemical sensitivity (MCS) tool for family physicians that is equivalent to fibromyalgia, myalgic encephalomyelitis/chronic fatigue syndrome and Postural Orthostatic Tachycardia Syndrome that reflects the evidence and protocols that MCS is a multi-system, biophysical, toxicological condition impacted by exposure to chemicals. (Sessional Paper No. 222) (Tabled by MPP Gélinas, France (Nickel Belt), 05/27/2024)***

The Minister replied on Nov 21<sup>st</sup>, 2024 that stated the following;

“People with MCS can receive services from interprofessional primary care teams across Ontario - and that they announced an increased investment of \$110M in 2024 for interprofessional team care.

"Ontario Health's Quality Standards are voluntary tools for health care practitioners and outline what high-quality care looks like for conditions and processes where there **are large variations in how care is delivered, or where there are gaps between the care provided in Ontario and the care patients should receive.**

While there is no Quality Standard for MCS, there may be Quality Standards that address symptoms related to MCS (e.g., asthma)."

The Minister then provides information on how to request such as standard be developed.

CareNow Ontario needs to follow-up on what steps are needed and what is required to develop a quality standard for MCS. These quality standards are developed at Ontario Health and not at the Ministry of Health.

#### **Comment #1:**

CareNow Ontario member Maureen MacQuarrie pointed out that the development of quality standards are very different than the development of CEP tools, and are more difficult to create, but still worth looking at.

Maureen MacQuarrie also commented that the Minister did not answer MPP France Gelinás's question and follow-up is required.

#### **Response:**

CareNow Ontario will keep advocating for the CEP tool for MCS and also explore the quality standards.

## 5. Attack on MCS: The Binkley Article:

- In September 2023, Dr. Farah Tabassum alerted CareNow Ontario to an article written by Dr. Binkley that was released on-line in the journal of Allergy Clinical Immunology Practice.
  - The hard copy of the article was published in November 2023.
  - The article takes a psychological approach to the causation of MCS.
  - Dr. Binkley is an associate professor, dept. of medicine, Division of Clinical Immunology and Allergy; and staff at St. Michaels and Sunnybrook.
  - Binkley KE. Multiple chemical sensitivity/idiopathic environmental intolerance: A practical approach to diagnosis and management. J Allergy Clin Immunol Pract. Forthcoming 2023; S2213-2198(23)00961-3. <https://doi.org/10.1016/j.jaip.2023.08.039>
  - Letters to the Editors (limit 500 words) submitted
    - Psychological approach is dangerous to patients.
    - Did not use recent research.
    - Outlined the biophysical toxicological school of thought.
- By:
- The Environmental Health Centre physicians lead by John Molot.
  - CareNow Ontario and Ontario Environmental Health Advocates: big thanks to Varda and Maureen.
  - ASEQ and their national organization.
  - These letters were published in February 2024 in the Journal of Allergy and Clinical Immunology.
  - In response, Dr. Binkley sent a rebuttal that was equally as harmful as the original letter.

## Advocacy Workplan for 2025

### 1. Advocacy for a Centre of Excellence

- Prior to the Election: Meet with the NDP, Green Party and the Liberals to gain their support for the release of the Implementation Report and the funding to implement the recommendations.
- All three parties are committed to the release of the report. It is necessary to remind them of this commitment.
- After the Election, meet with the new Minister of Health.

### 2. Primary Care Tools

1. Follow-up re: the letter sent to the Minister of Health requesting:
  - that the Ministry of Health fund CEP to develop a tool for MCS using approved experts and the same process as was used for the other three tools.
  - that the MOH fund a process to develop clinical guidelines for MCS.

No response was received from the Minister.

MPP France Gelinias will be requested to follow-up on the letter and the question.

2. Follow-up with Centre for Effective Practice re implementing a distribution strategy so

that more physicians and nurse practitioners become aware of the tools for FM, ME/CFS and POTS.

3. Follow-up with Ontario Health re developing a Quality Standard re MCS.

## 2. Hospitals as safe spaces for people with ES/MCS & EH

### Step 1:

Varda Burstyn is in the final stages of developing a kit for patients with ES/MCS & EHS to advocate for a care plan when they go to their local hospitals.

This kit includes a step-by-step guide, sample accommodation agreements that you can share with your hospitals, sample letters you need to get from your physicians and so on.

This tool kit will be uploaded to the CareNow Ontario website once it is completed.

CareNow Ontario will hold a webinar with members and friends to walk through the kit and show you how to use it with your physicians and hospitals.

### Step 2:

CareNow Ontario will advocate with the Ontario Hospital Association that all Hospitals adopt these policies and procedures.

Stay tuned for more information on the webinar to be hosted early in 2025.

### Question #1:

Do people have experience using the masks that are made with activated charcoal? Is that something that is commonly used by the people with MCS? And do they find that they help?

### Response:

Members responded that they think they are helpful and it depends on how the charcoal was prepared.

## 5. Treasurer's Report

Presented by Adrianna Tetley, Treasurer

Financial Statements for 2023 were presented.

- Revenue: \$12,183
- Expenses: \$9,310
- Net (positive) of \$2,873
  
- Net assets on Dec 2023: \$7,166
  
- CareNow Ontario continues to minimize expenses for the year, the organization projected \$1,000 Net surplus and projected \$8,166 Net Assets for Dec 2024.

### **Looking Forward to 2025:**

- Reviewed and streamlined every expense.

- Forecast revenue in the range of \$10,000, expenses in the range of \$9,000 with annual surplus of \$1,000.

***Sustainability for CareNow Ontario:***

- CareNow Ontario will continue to be sustainable into the future.
- Annual fundraising campaign (our database and Board’s network of friends and family).
- Minimizing expenses.
- The \$7,166 to be held in reserve to manage any unexpected expenses and to be prioritized for any advocacy work that may need to undertake.

***Question #1:***

What is the annual cost to maintain the CareNow Ontario website?

***Response:***

- Approx. \$3,000 that includes hosting fee, domain fee, and IT consultant fee.

**Motion: Financial Statements 2023**

**Be it resolved** that the Financial Statements (notice to reader) of CareNow Ontario as reviewed by chartered accountant, Welch LLP and as presented for the year ended December 31<sup>st</sup>, 2023 be approved.

Moved by: Adrianna Tetley  
 Seconded by: Keith Deviney  
 Unanimous: Motion Carried.

**Motion: Auditors for 2024**

**Be it resolved** that Welch LLP chartered accountants be appointed auditors for financial reviews and financial matters for CareNow Ontario for the year 2024 at the appropriate remuneration as determined by the Board of Directors.

Moved by: Adrianna Tetley  
 Seconded by: Keith Deviney  
 Unanimous: Motion Carried.

**6. Nomination Report**

Presented by John Doherty, Secretary

Pursuant to the MEAO by-laws of 2018 section 4.3, the board of CareNow Ontario is a maximum of seven (7) directors. The Board currently has five directors.

Denise Magi, Chair and President, has completed her three-year term. After 16 years of dedicated service, due to medical related reasons, Denise with heavy heart, has decided to not stand for re-election.

John Doherty, Secretary and Keith Deviney, Vice Chair have completed two years of their three-year term.

Adrianna Tetley, Treasurer, and Laurie Menard, Director have completed one year of their three-year term.

The CareNow Ontario By-laws allow for a board of a maximum of 7 Directors. Therefore, the CareNow Ontario Board was seeking nominations for up to 3 Board members.

A Call for Nominations was issued on August 17<sup>th</sup>, 2024 seeking nominations for up to 3 Directors.

Philip De Groot submitted his nomination. The CareNow Ontario Board supports Philip's nomination for a three-year term. Bio was circulated for review.

Philip was given an opportunity to address the AGM with a brief introduction.

#### **Roll Call Vote:**

Philip De Groot is standing for election as a Director for CareNow Ontario for a three-year term.

A roll call vote was conducted via Zoom for the nominee and result announced.

Results of Roll Call Vote for Philip De Groot:  
16 in Favour, 2 Abstained

**\*\*Philip De Groot elected.\*\***

#### **CareNow Ontario Board of Directors 2024/25:**

- Philip De Groot, Director
- Keith Deviney, Vice Chair and Vice President
- John Doherty, Secretary
- Laurie Menard, Director
- Adrianna Tetley, Treasurer

#### **7. Directors' Report – Presentation by President:**

CareNow Ontario President Denise Magi, presented the Directors' Report. This report details the major activities from November 1<sup>st</sup>, 2023 AGM to present and the decision to resign as President.

Denise Magi thanked the Directors and the administrative assistant for their hard work and contributions to CareNow Ontario.

#### **8. Appreciation of Denise Magi:**

- After 16 years of dedicated service, due to medical related reasons, Denise Magi with heavy heart, has decided to resign as President of CareNow Ontario.
- CareNow Ontario Board of Directors, colleagues and friends wanted to extend their gratitude and appreciation to the many years of service to the organization. Speeches, letters, videos and an award was presented to Denise Magi during the AGM.
- In recognition of her many years of dedication and gratitude for her tireless work, CareNow Ontario presented Denise Magi with a plaque..
- The Board recognizes Denise Magi's accomplishments and efforts to the organization and invites Denise to continue to serve as "Past President" in a non-voting capacity according to her availability.

## **10. Other Business**

No other business

## **11. Adjournment**

### **Motion:**

Be it resolved the Annual General Meeting, November 28<sup>th</sup>, 2024 be adjourned

Moved by Laurie Menard

**Meeting Adjourned at 2:48 p.m.**

## Appendix A

### VOTERS LIST – 2024

Last Name	First Name	Zoom / By Proxy / By Phone
Al-Awadi	Fadi	By Proxy
Coatsworth	Cam	By Proxy
De Groot	Philip	Zoom
Deviney	Caroline	By Proxy
Deviney	Keith	Zoom
Doherty	John	Zoom
Gemmell	Christina	By Proxy
Halapy	Erika	Phone
Jiwani	Izzat	By Proxy
Johnston	Eleanor	Phone
MacQuarrie	Maureen	Zoom
Magi	Denise	Zoom
Menard	Laurie	Zoom
Tetley	Adrianna	Zoom
Tetley	Casey	By Proxy
Tetley	Kim	By Proxy
Tetley	Peter	By Proxy
Vandenbroek	Mary - Lou	By Proxy