



Renewal Taskforce

Paper 1: Desired Outcomes and Issues

November 7, 2011



Executive Summary

The Renewal Taskforce was mandated by the national board of the Multiple Sclerosis Society of Canada in August 2011 “to examine all aspects of the MS Society, including its multi-level structure and roles and responsibilities, and to enable the MS Society to effectively and efficiently deliver upon its mission: To be a leader in finding a cure for multiple sclerosis and enabling people affected by MS to enhance their quality of life. “

This first phase of Renewal is focused on the identification of desired outcomes resulting from this process. Thus far, the taskforce has identified four desired outcomes:

- 1. With people living with MS at the center of our work, the MS Society will deliver high-quality service and program offerings, including influencing positive change through government advocacy, that reflect the unique needs of the communities and people we serve.**
- 2. The MS Society will have a research program that can sustainably fund the best Canadian-led research focused on MS. The research we fund will have direct linkage to enhancing quality of life for people living with MS today and finding the cause of and, ultimately, a cure for MS.**
- 3. The MS Society will have a revenue generation and spending model that is sustainable in the long-term and maximizes our ability to deliver on our mission.**
- 4. The MS Society will have an effective and efficient model of operation and governance that best serves those living with MS and meaningfully engages volunteers and staff in fulfilling our mission. We will be united, streamlined and respectful that some functions are uniquely executed locally while others are best carried out regionally or nationally.**

The taskforce is seeking reaction to the desired outcomes identified and the issues associated with each. Has anything been missed? Do stakeholders agree or disagree? What solutions might there be available to achieve these desired ends?

Feedback to this paper will be compiled and provided to the taskforce as inputs into the next phases.

Renewal Taskforce

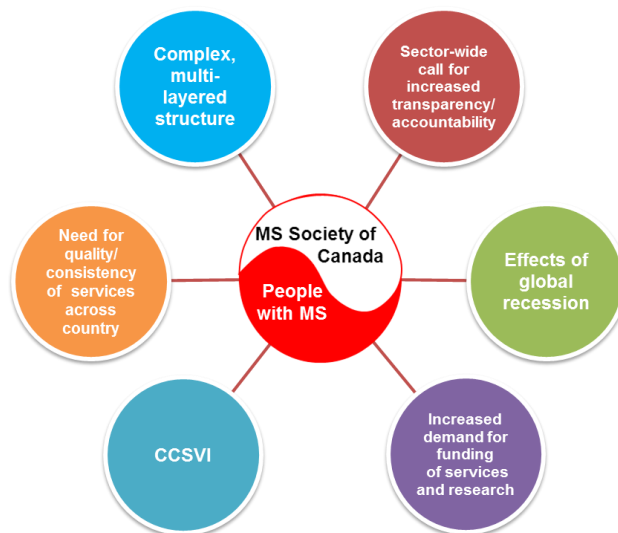
Paper 1: Desired Outcomes and Issues

Background:

The Renewal Taskforce was mandated by the national board of the Multiple Sclerosis Society of Canada in August 2011 to “examine all aspects of the MS Society, including its multi-level structure and roles and responsibilities, and to enable the MS Society to effectively and efficiently deliver upon its mission.” The full terms of reference and the taskforce membership list are included as appendices at the end of this document.

Why Renewal?

The graphic and explanation below depicts some of the many factors impacting the MS Society today. As a whole, we know that the global economic outlook remains uncertain and, as a charitable organization, we must constantly strive for the most efficient uses of the donations entrusted to us by strengthening our financial and operational management. With an estimated 1,000 new cases of MS in Canada every year, the demand for support from the MS Society continues to grow even in times when our revenue is under significant pressure. For example, in 2011, we know that MS Walk revenue is markedly lower compared to 2010. This directly impacts our ability to fund services at the community level. This type of pressure gives us the impetus – and the urgent need – to look for improved ways to deliver on our mission. The Renewal Initiative recognizes the complexities we face as an organization and provides us with an opportunity to address them with a bold spirit, leaving no potential solution off the table.



- **Demand for services and MS research funding:** The number of people living with MS continues to rise and so does demand for our services. In addition, the MS Society faces increasing financial pressure in our ability to fund research. In 2010, we were unable to fund all recommended research proposals as put forward by our voluntary national medical advisory committee.
- **Need for quality/consistency of services:** People living with MS should have access to high-quality services regardless of geography.
- **Structure:** The MS Society has a complex structure involving over 100 offices and decision making bodies (i.e. governance boards) including chapters, divisions and a national office.
- **Need for increased transparency and accountability:** The not-for-profit sector, government regulators, media outlets and donors all recognize that we are in an era where greater transparency is both needed and expected.
- **Recession:** The recession has impacted economies both domestically and worldwide creating a difficult fundraising environment.
- **CCSVI:** Widespread attention about this new treatment theory for MS changed the landscape in which we operate, creating both opportunities and challenges.

In short, the environment provides us a very real impetus for change. If we do not change, we risk our ability to be as effective as possible in delivering on our mission.

Timeline and Phases

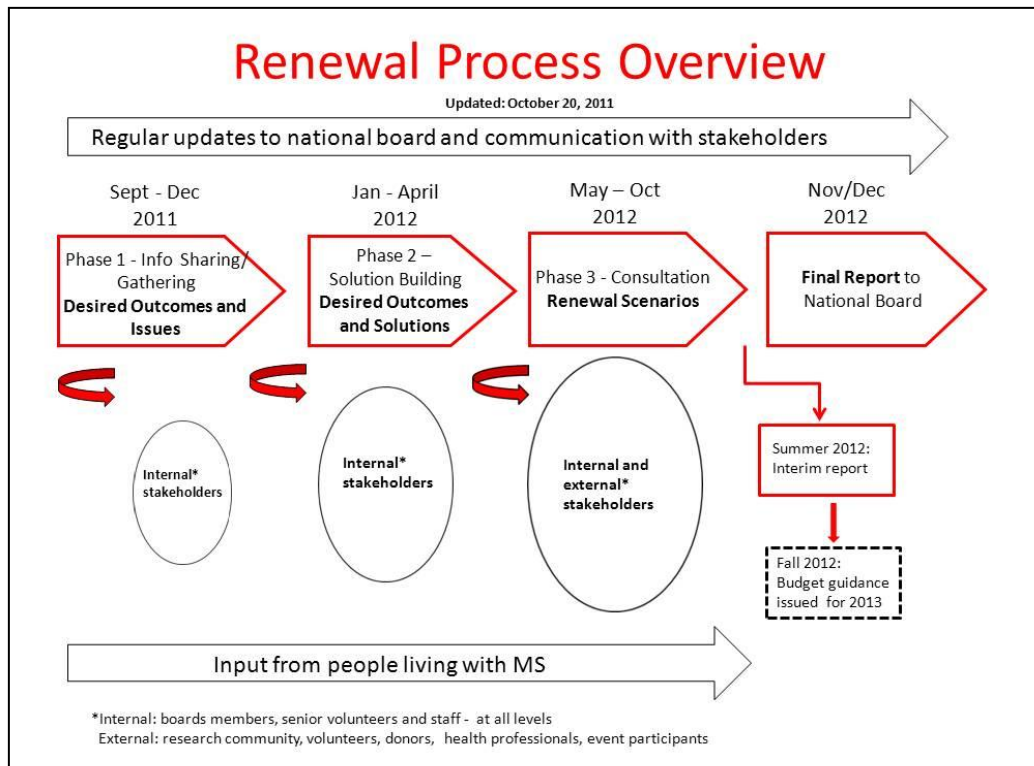
The Taskforce began its work in September 2011 and will submit its final report to the national board of directors in the fall of 2012. This process will involve three distinct phases of stakeholder engagement.

- **Phase 1 – Information Sharing and Gathering.** The purpose of this phase is to solicit views on the core issues facing the MS Society and the ideal vision of how these issues can be addressed. The Taskforce will circulate *Paper 1: Desired Outcomes and Issues* in early November primarily to internal stakeholders (board members, senior volunteers and staff – at all levels) for input by the end of December 2011
- **Phase 2 – Solution Building.** The purpose of this phase is to generate potential solutions to issues identified in the first phase of the process. The Taskforce will circulate *Paper 2: Desired Outcomes and Solutions* in early 2012 to stakeholders for input from January to March 2012.
- **Phase 3 – Consultation.** The purpose of this phase is to build upon the first two phases to compose defined scenarios of change. The Taskforce will circulate

Paper 3: Renewal Scenarios in late May 2012 to internal and external stakeholders for input until later summer/early fall 2012.

During phase 3, the taskforce will submit an interim report of recommendations to the national board. The board will consider these recommendations in formulating budget guidance for the 2013 budgeting cycle.

A final report of recommendations will be submitted to the national board in the fall of 2012.



Desired Outcomes and Issues

Introduction to Desired Outcomes and Issues

In September 2011, the taskforce met to discuss the broad range of issues that the MS Society faces. In bringing issues to the table, taskforce members were asked to consider the MS Society in the broadest view possible and to draw upon their own experiences as members of the MS family. After a lengthy discussion and further conversations, the taskforce identified four core issues and framed them in the context of an ideal outcome that will follow from the Renewal process.

Please know these desired outcomes and the discussion notes that follow are the first of a multi-stage process. Developing the “how-to” for achieving these outcomes will be addressed in later stages of this process. Decisions related to implementation *are not* within the scope of this paper. In fact, all possibilities remain open in terms of how we achieve the desired outcomes.

At this early stage, the taskforce is seeking reaction to the outcomes identified. Has anything been missed? Do you agree or disagree? Do you have potential solutions to offer to the issues presented? At the end of this paper, you will see the methods we’ve developed to solicit your input. Your feedback will be compiled and provided to the taskforce as inputs into the next phases.

Thank you in advance for any input you may provide.

Desired Outcome 1: With people living with MS at the center of our work, the MS Society will deliver high-quality service and program offerings, including influencing positive change through government advocacy, that reflect the unique needs of the communities and people we serve.

Issue Discussion and Background:

The delivery of health care services in Canada is highly complex. The federal government provides some funding for health care through complex provincial and territorial agreements and sets broad, overarching policy directives through legislation and regulation. Meanwhile, provinces and municipalities fund and deliver health care services through a variety of means. People living with MS must navigate the system carefully to find the support they need.

At the same time, the MS Society of Canada conducts crucial work that is not supported through other means including the provision information and referral services, financial assistance and wellness initiatives such as social and recreational programs. This complicated environment brings forth a number of questions that need to be addressed through this initiative so that the MS Society can deliver meaningful programming to people touched by MS:

- Should we offer a core menu of services available consistently across the country supplemented by regional offerings?
- Are MS Society service and program offerings currently tailored to the unique needs of communities while being accountable to a defined standard of quality?
- Do we effectively recognize and take advantage of pre-existing regional programs/services that exist for people touched by MS and customize our offerings based on this knowledge?
- Like other service industries, is it feasible to develop a “standard of service” for those we serve?
- Should we proactively partner with other like-minded organizations in serving those with MS?
- How well do we communicate the service and program offerings we have?
- Economic factors affect not just the organization but people living with MS. How do we handle increased demand for services during times of economic difficulty?
- How do we know if we are providing meaningful enhancement to the quality of life of people living with MS?

Desired Outcome 2: The MS Society will have a research program that can sustainably fund the best Canadian-led research focused on MS. The research we fund will have direct linkage to enhancing quality of life for people living with MS today and finding the cause of and, ultimately, a cure for MS.

Issue Discussion and Background:

The MS Society of Canada provides global leadership in the effort to end multiple sclerosis. Research we've funded has resulted in substantial progress in areas such as pediatric MS, early diagnosis through MRI and the relationship between genetic and environmental susceptibility factors, to name only a few. Additionally, with the launch of the endMS Research and Training Network in 2008, we've played a key role in galvanizing over 950 researchers and 65 academic and health institutions to direct focused attention to multiple sclerosis. This success has led to increasing interest in MS and a spike in the number of research proposals submitted to the MS Society for potential funding. This puts us in the precarious position of not being able to fund all meritorious research. Through this lens, the following questions must be addressed:

- In the long-run, are we positioned to sustainably fund the best and most-promising Canadian-led MS research?
- Do we fund research in the categories that address the needs of people with MS? i.e. preventing, treating, enhancing quality of life, curing MS
- Do we have the resources to fund large, Canadian-led, multi-center trials of promising MS research?
- Are we structured in a way that allows each level of the organization to contribute to research equitably?
- Have we set up an unintentional competition between funding research and other mission-related activities?
- How well are we articulating the benefits or outcomes of research to the MS community at large?
- How do we ensure that people with MS have a real stake in our research program?

Desired Outcome 3: The MS Society will have a revenue generation and spending model that is sustainable over the long-term and maximizes our ability to deliver on our mission.

Issue Discussion and Background:

Unlike the majority of health charities, the MS Society of Canada does not receive substantial funds from government to help us deliver on our mission. In fact, 97% of MS Society revenue comes from individual and corporate donors. The revenue comes from a variety of sources including pledge-based events, direct mail, bequests, corporations and major gifts. That we are self-funded works well in that we are not reliant on the changing preferences of governments but we do become more susceptible to environmental factors such as a poor economy, reduced consumer confidence and higher levels of government and public scrutiny on cost of fundraising issues. Within this context, how do we address the following issues?

- Does the MS Society of Canada have a revenue generation model that is sustainable over the long-term?
- Are we spending revenue in the right categories that maximizes our ability to deliver on our mission?
- Does our complex structure hinder our ability to spend funds raised in the areas most needed?
- Is our revenue generation model optimized for raising the most revenue at the lowest cost?
- Are funds being spent where they can have the most impact on the delivery of our mission?
- Do we have the right mix of revenue generating activities?
- Should we aim to have increased revenues from government sources?
- Should we aim to have fee-based revenues?
- Do our current revenue sharing practices encourage a donor-centric model of fundraising in which donors determine what to support?

Desired Outcome 4: The MS Society will have an effective and efficient model of operation and governance that best serves those living with MS and meaningfully engages volunteers and staff in fulfilling our mission. We will be united, streamlined and respectful that some functions are uniquely executed locally while others are best carried out regionally or nationally.

Issue Discussion and Background:

Typical of many national health charities, the MS Society is built upon the basis of multiple levels playing a role in overall operations. Here at the MS Society, chapters, divisions and national office co-exist and make decisions on how to best serve our mission. As times have changed, so have we; over the course of six decades, we have grown and evolved in complex ways.

Throughout our history, volunteers have been essential to all that we do. They are at the frontlines, meeting with clients and welcoming participants to MS Society fundraising events. They also work diligently in the background, providing leadership on boards and committees and connecting us with corporate donors so that we can raise funds for our mission. Supporting this important work are staff members who have made the conscious decision to make the MS Society their employer of choice.

Now is the time to review this evolution and consider how volunteers and staff can be more tightly woven into our work.

- Are we structured in a way that best allows us to deliver on our mission?
- How can we intensify meaningful volunteer and staff engagement at all levels of the organization?
- Can we replicate industry best practices in the areas of recruitment, retention and engagement of volunteers and staff?
- Do the individual parts work in concert to support the whole without overlap of duties, effort and spending?
- Does the current structure allow for consistency of policy application and sharing of best practices?
- Is the current governance model suitable and effective?
- Do we have infrastructure costs that can be reduced to increase net revenue?
- If we were establishing the organization today, what might we do differently from when the MS Society was established nearly 65 years ago?
- How do we encourage innovative practices to engage the youth of today as volunteers and staff of tomorrow?

Your Feedback on this Paper

The taskforce is seeking feedback on the core issues and outcomes identified in this paper. You can structure your feedback by answering the following three questions:

- 1) What is your reaction to the desired outcomes and issues identified in this paper?
- 2) Have any issues been missed? Please elaborate.
- 3) What solutions do you propose to the issues identified in this paper and any that you have identified yourself?

You can provide this feedback in one of two ways:

- 1) Send an email to renewal@mssociety.ca
- 2) Answer anonymously through this weblink www.surveymonkey.com/s/9HWMCZ8 (note this survey will close on December 16, 2012, 12pm ET)

The taskforce welcomes both individual and group (i.e. chapter or division boards, committees, staff departments etc.) feedback. The feedback will then be used in the development of *Paper 2: Desired Outcomes and Solutions*.

Contact

If you have any questions about the process or about this paper, please feel free to contact Stewart Wong, director of communications and Renewal Initiative at stewart.wong@mssociety.ca or 416-967-3025 or email renewal@mssociety.ca

APPENDIX 1: TASKFORCE TERMS OF REFERENCE

Multiple Sclerosis Society of Canada Renewal Taskforce - Terms of Reference

Approved by the National Board of Directors of the MS Society of Canada on August 24th, 2011.

Purpose

To examine all aspects of the MS Society, including its multi-level structure and roles and responsibilities, and to enable the MS Society to effectively and efficiently deliver upon its mission: To be a leader in finding a cure for multiple sclerosis and enabling people affected by MS to enhance their quality of life.

Objectives

The taskforce shall provide actionable recommendations to the national board with respect to:

1. The strategy for engaging the MS community and stakeholders at the national, divisional and chapter level in the renewal process.
2. The future structure of the MS Society at the national, divisional and chapter levels including roles and responsibilities and the requisite accountability framework.
3. Opportunities to increase revenue, reduce duplication, streamline operations, improve service delivery, realize cost efficiencies, enhance research and mitigate risk to the organization.
4. The communication strategy to ensure openness and transparency during the renewal and change processes.
5. The implementation of best practices for all levels of the MS Society.

Scope of Work

In meeting its objectives, the taskforce shall:

1. Research change management processes and options for organizational renewal including analysis of the consultation, implementation and communication methods used by other charitable organizations to affect organizational change and their outcomes in order to benchmark against leading organizations.
2. Identify gaps and inefficiencies in the delivery of client and administrative services, as well as other activities of the MS Society, and examine alternative service delivery models.
3. Identify and analyze the challenges and successes experienced by the MS Society as a means for establishing best practices.

4. Coordinate the renewal process with other important planning processes undertaken by the MS Society of Canada. This may include, but is not limited to, annual budgeting processes and strategic planning processes.

Responsible to

MS Society of Canada - National Board of Directors.

Authority

The renewal taskforce provides advice and recommendations to the national board but may not exercise the authority of the national board.

The taskforce shall report to the national board at each of its regular meetings (i.e. three times per year) and may on each of those occasions present an interim report with actionable recommendations for the board's consideration. The taskforce shall present a final report to the national board upon culmination of its work.

Composition

1. Size – The taskforce will be comprised of 17 members including the chair.
2. Chair – The chair will be chosen by the national board from amongst its current members.

Members – Members of the taskforce shall be appointed by the national board. The following criteria are to be considered:

- Members shall be chosen based upon the diversity of perspective and level of experience they bring from all levels of the organization to provide a balanced representation of the interests within the MS Society.
- Members of the taskforce shall include persons with MS and others affected by MS.
- To the extent possible, members will represent the linguistic and geographical diversity of Canada, as well as gender balance.
- Members shall include:
 - 3 past or present members from chapter boards of directors;
 - 2 chapter staff members;
 - 3 past or present members from divisional boards of directors;
 - 2 divisional staff members;
 - 3 past or present members of the national board of directors (one present member of which to act as chair);
 - 2 national staff members;
 - The president and chief executive officer of the MS Society;
 - The national scientific and clinical advisor.

Terms of office

1. Chair – The chair will serve for the duration of the project which is anticipated to be 18 to 24 months from the date of appointment.
2. Members – Members will serve for the duration of the project which is anticipated to be 18 to 24 months from the date of appointment.

Meetings

Meetings of the taskforce will be held on an as needed basis. It is anticipated that the taskforce will meet approximately six times a year. Meetings will be held usually by teleconference to minimize costs, with occasional meetings held in person to facilitate relationship building. All efforts will be made so that agendas and supporting documents for each meeting will be sent at a minimum one week in advance. A written summary of meeting discussions will be kept and submitted for approval at a future meeting.

Norms

The taskforce shall operate on a consensus model which will follow the following precepts:

1. Inclusive and participatory – as many taskforce members as possible shall be involved in discussion and in the formulation of recommendations to the national board.
2. Focused on the whole – members shall strive to advance the interest of all people with MS.
3. Solution-oriented – members shall strive to emphasize common agreement over differences and reach effective conclusions using compromise and other techniques to avoid or resolve mutually-exclusive positions within the taskforce.
4. Failing the ability to reach consensus, the taskforce will use traditional majority voting to bring recommendations and advice to the national board. In this case, the chair will explicitly tell the national board about the absence of consensus and what the other opinions are relating to the absence of consensus.
5. To ensure consistency of message, the chair of the taskforce or the CEO will serve as the voice of the taskforce to internal and external stakeholders including media. To facilitate input from those they represent, members can speak about the work of the taskforce and their membership in it, but cannot speak on behalf of the taskforce itself.

6. Members of the taskforce shall be subject to the *Conflict of Interest Guidelines for Directors and Officers* and to the *Privacy and Confidentiality Policy* of the MS Society of Canada and will be required to acknowledge their agreement to abide by these policies and guidelines at least annually.

Staff support

The director, Communications and Renewal Initiative has been appointed to lead this process within the president's office. The process will also be supported by external counsel for additional rigour and change management expertise. External legal counsel may be sought on an as-needed basis.

Convening and other administrative support for the taskforce shall be provided by MS Society staff as delegated by the president and CEO.

Other resources:

Additional MS Society volunteers, staff members or external experts may be invited to participate in an advisory capacity. The taskforce may not commit expenditures for travel, expert advice or consultants except through the CEO.

Communication with the National Board of Directors

The taskforce shall report to the national board through its chair. It is the responsibility of the national board to approve, reject or return for re-consideration the recommendations of the taskforce.

Approval/Review Date:

During the life of the taskforce, its terms of reference are to be reviewed annually by the national board and are to be amended if deemed necessary pending review. If the taskforce does not complete its work within the 18-24 month horizon outlined, the national board will determine how to proceed to ensure that the objectives of the taskforce are met.

APPENDIX 2: TASKFORCE MEMBERSHIP

| Renewal Taskforce: Members | |
|---|---|
| Name | MS Society Affiliations |
| National Board Members | |
| David Garton (Chair) | Member, National Board; Member, National Executive Committee |
| Marilyn Lenzen | Member, National Board; Chair, BC & Yukon Division, Board |
| Valerie Hussey | Member, National Board; Vice-Chair, Ontario Division Board |
| National Senior Staff | |
| Ken Mayhew | Chief Development Officer |
| Jamie Hall | Chief Financial Officer |
| Yves Savoie | President & Chief Executive Officer; President, Ontario Division |
| Divisional Board Members | |
| Daniel Larouche | Past member and chair, Quebec Division Board; Past Chair, National Board |
| Chuck Ford | Member and past chair, National Governance Committee; Immediate past chair and member, Atlantic Division Board; Past member, National Board |
| Jeannette Edwards | Past member and chair, Manitoba Division Board; past member, National Board |
| Divisional Staff | |
| Louis Adam | President, Quebec Division |
| Neil Pierce | President, Alberta and Northwest Territories Division |
| Chapter Board Members | |
| Carey Mogden | Chair, Calgary Chapter; 1 st vice-chair, Alberta and Northwest Territories Division Board |
| Marie-Josée Comtois | Past chair, South Shore (Montreal) Chapter; Past member Quebec Division Board; Past chair, Client Services Committee |
| Marie Vaillant | ON Division Board member; Chair, Client Services Committee; Member, Chapter Relations Committee; Past chair Ottawa Chapter |
| Chapter Staff | |
| Ann Stewart | Executive Director, Lethbridge Chapter |
| Todd Abercrombie | Executive Director, South Vancouver Island Chapter |
| National Scientific and Clinical Advisor | |
| Paul O'Connor | Director, MS Clinic, St. Michael's Hospital, Toronto; Professor of Neurology, University of Toronto |