Canadian MPS Society
for Mucopolysaccharide & Related Diseases

2025 National
FAMILY CONFERENCE

HILTON Mississauga, ON

18-20 JULY, 2025

Living our best lives

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Message from the Chair of the Board of Directors, Melissa Bilodeau

It is with great pride that I welcome you to our 2025 National Family Conference. Having been a part of this remarkable organization for many years, I am deeply honored to celebrate the 40th anniversary of the Canadian MPS Society with all of you.

This organization was born from a need that every parent here understands all too well—the profound, overwhelming search for answers and support that begins the moment a diagnosis is given. Since then, we've grown into a powerful force advocating for families and supporting them daily.

Sheila Lee started this organization over 40 years ago because she needed help with her daughter Brandy, and thanks to her vision, we are still going strong. With each new chapter of growth, and with the rise of the digital age, our ability to raise awareness has expanded dramatically. On International MPS Day alone, our content reached 1.4 million views across multiple platforms. At the conference, we'll dive deeper into how that incredible impact came to life.

As someone personally affected by MPS, I can speak firsthand about the importance of the work we do. At the core of everything is helping families. Whether a newly diagnosed family needs reliable information from our website or someone to talk to, we are here to offer both. Our Family Assistance Program continues to thrive, and this year, it will grow even further.

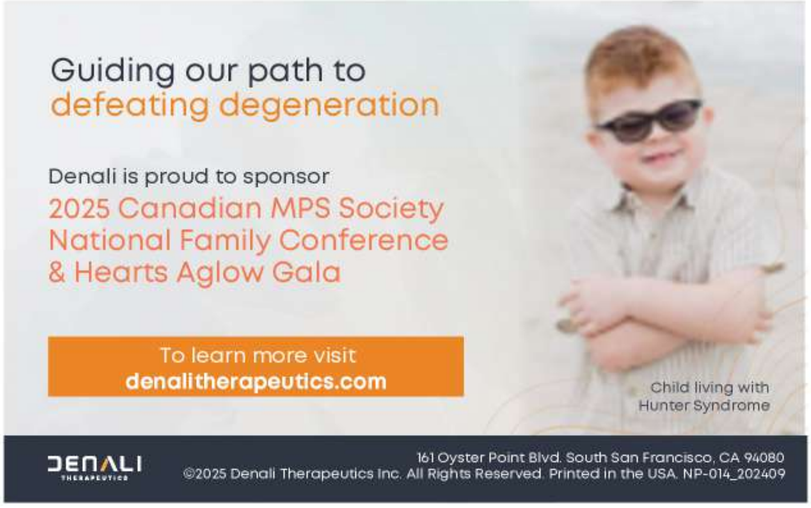
We're excited to share that a new funding strategy is in development and set to launch by the end of August. This will provide additional resources and help us extend our services to our family members.

As you hear from leading physicians and clinical teams about the latest advancements, we've also carved out time for something just as powerful: opportunities to connect—both with fellow parents who share this journey and with the experts whose work directly impacts it. Share experiences, build relationships, and take full advantage of these moments to learn, engage, and feel supported.
I hope you enjoy the conference, the children's program, and our dinner event. I look forward to connecting with all of you over the next three days!

Warm regards,

Melissa

Mellisa Bilodeau Chair, Board of Directors



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Ultragenyx is proud to sponsor the Canadian MPS Society 40th Anniversary Gala and to support its ongoing work on behalf of the MPS Community.

To learn more,
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MRCM-UGNX-00674 April 2025

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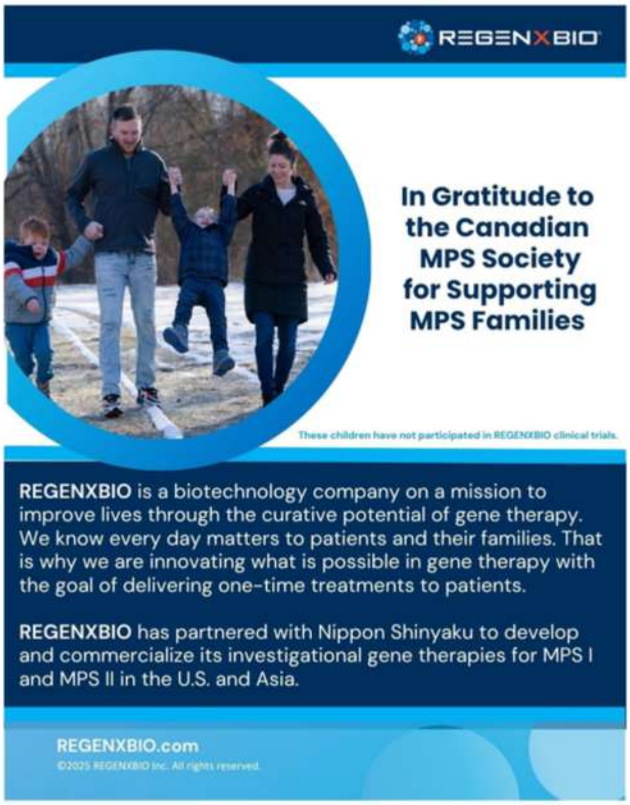

REGENXBIO

In Gratitude to the Canadian MPS Society for Supporting MPS Families

These children have not participated in REGENXBIO clinical trials.

REGENXBIO is a biotechnology company on a mission to improve lives through the curative potential of gene therapy. We know every day matters to patients and their families. That is why we are innovating what is possible in gene therapy with the goal of delivering one-time treatments to patients.

REGENXBIO has partnered with Nippon Shinyaku to develop and commercialize its investigational gene therapies for MPS I and MPS II in the U.S. and Asia.

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Welcome to the 2025 MPS National Family Conference

As I embark on the second half of my first year at CanMPS I am extremely excited to meet all of the participants here. The conference has been made possible by so many: all of our sponsors, donors, gift in kind donors, our board of directors, volunteers and most of all the families who were able to make the trip.

Our agenda has been very intentional to provide a balance of information and has lots of time for people to connect. Time to enjoy other people's company and sharing experiences.

We have created a QR code you can add pictures to the folder. Never know it could be available later for sale like a yearbook!

2025/26 year will be full of reinvigorating our program services and creating an aggressive fundraising plan. Growing our membership and our volunteer base is critically important.

I invite your ideas, comments, and feedback.

Enjoy the conference!

Sincerely,

Mary Bone, Executive Director

Mary Bone

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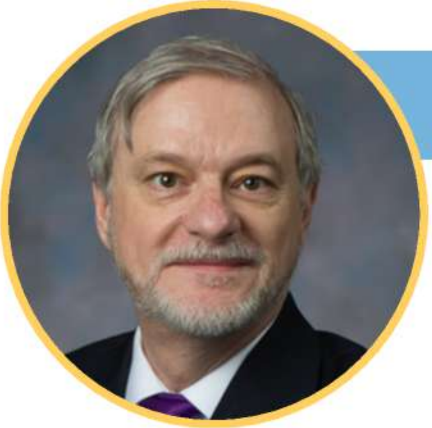
Our Speakers

DR JOHN J. MITCHELL

Dr. John Mitchell is a physician-scientist specializing in rare metabolic diseases, commonly known as orphan diseases, with particular expertise in enzyme deficiency disorders such as phenylketonuria (PKU) and lysosomal storage disorders.

He is actively involved in developing and implementing cutting-edge therapeutic approaches including chaperone therapies, enzyme replacement therapies, and gene therapies, while also maintaining a keen interest in health policy, specifically examining how Canadian federal and Quebec provincial governments evaluate, approve, and provide coverage for orphan disease treatments. He has participated in the development of national and international clinical guidelines for MPS II, MPS IVA and MPS VI.



DR KIM MCBRIDE

Dr. McBride has expertise in the clinical care of individuals with rare diseases and a mission to lead in translational genetics, applying skills at bridging basic and clinical science to affect change in understanding, diagnosing and treating rare and devastating disorders in children.

DR BETH POTTER

Dr. Beth Potter is a faculty member in the School of Epidemiology and Public Health since 2007, holding a PhD in epidemiology from the University of Western Ontario. Her research focuses on improving healthcare and outcomes for children with rare genetic diseases, particularly inherited metabolic diseases. Through multi-centre collaboration and patient partnership, she addresses the evidence gap in rare disease care.

Dr. Potter leads INFORM RARE and the Canadian Inherited Metabolic Diseases Research Network (CIMDRN), pan-Canadian networks that conduct observational studies and clinical trials to evaluate outcomes and interventions for children with rare diseases. She also researches disease screening, including newborn and prenatal screening.

Our Speakers

DR. ANEAL KHAN

Dr. Khan has worked at the Hospital for Sick Children, University Health Network, McMaster Children's Hospital, Alberta Children's Hospital and now works primarily through his community clinic called M.A.G.I.C. (Metabolics and Genetics in Canada).

He was the first physician in the world to treat Fabry disease and Gaucher disease using Gene Therapy, the first in Canada to use Liver Cell Transplant and Gene Therapy to treat Urea Cycle Diseases and is experienced in using research drugs injected directly into the spine.

DR. EVA MAMAK

Dr. Eva Mamak is a board-certified clinical neuropsychologist at the Hospital for Sick Children in Toronto. She holds a PhD in School Psychology from UNC-Chapel Hill and completed her post-doctoral fellowship in Pediatric Neuropsychology at SickKids.

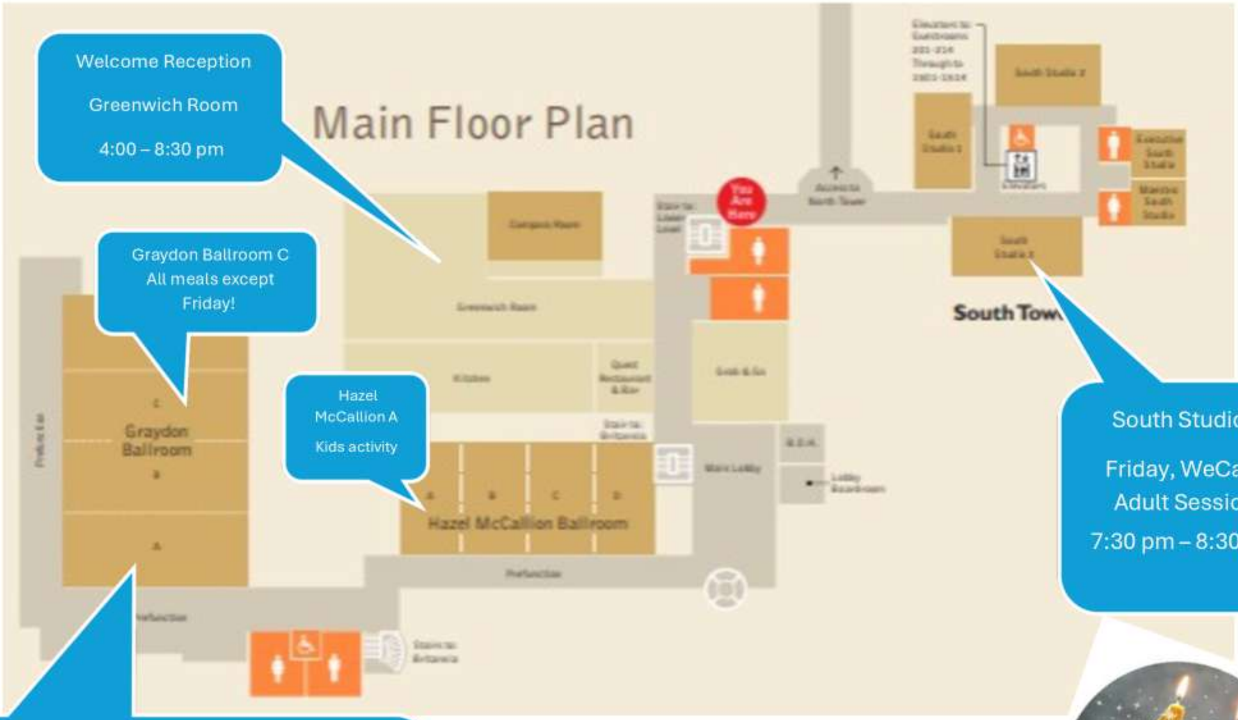
Dr. Mamak's clinical work focuses on evidence-based assessment of children with rare diseases, genetic conditions, and neurological disorders. Her research examines neurocognitive outcomes in rare diseases through multi-disciplinary studies. Dr. Mamak also coordinates the post-doctoral fellowship program in clinical neuropsychology at SickKids.

LISA FEITELBERG

Lisa Feitelberg, MSW, RSW, is a registered social worker in the Division of Clinical and Metabolic Genetics at The Hospital for Sick Children (SickKids) in Toronto. With a background in pediatric healthcare, Lisa has dedicated her career to supporting children and families as they navigate the challenges of complex medical diagnoses. She is passionate about family-centered care and the emotional wellbeing of caregivers, and brings a trauma-informed, compassionate
approach to her work.

Floor Plan

Meadowvale Hilton Mississauga Floor Map – 2025 MPS National Family Conference



Welcome Reception

Greenwich Room

4:00 – 8:30 pm

Graydon Ballroom C
All meals except
Friday!

Hazel
McCallion A

Kids activity

South Studio 3

Friday, WeCare
Adult Session

7:30 pm – 8:30 pm

Graydon Ballroom A & B

All Conference sessions

Hearts Aglow Dinner

Agenda

Friday, July 18, 2025			
4:00 pm	8:00 pm	Registration Opens	See the welcome team at the front table, make sure you get your nametag & lootbags.
4:00 pm	7:30 pm	Welcome, meet & greet drop in Greenwich room	Join us for some beverages and a lite hors d'oeuvres (snacks) get to know some of the participants.
7:30 pm	8:30 pm	We Care – for Adults South Studio 3	Join in on a group session that is lead by MPS families for MPS Adults. Led by Katrina!
7:30 pm	8:30 pm	We Care NextGen - for Youth Hazel McCallion B	This is a special WeCare session for the NextGen population; no parents allowed! Led by Sarah & Jessica
7:30 pm	9:30 pm	Fun Room - Hazel McCallion A	GAMES This is for anyone that doesn't want to attend WeCare and would like to continue the evening.
Saturday, July 19, 2025			
6:30 am	8:45 am	Graydon C	Breakfast, buffet style
8:00 am	8:30 am	Children's Program Drop-off Hazel McCallion A	Children's Program Drop-off, meet the organizers and the volunteers.
9:00 AM	9:30 AM	Graydon Ballroom A&B	Opening Remarks (3 speakers) Melissa Bilodeau - Welcome Mississauga. School of Music - National Anthem Mary Bone - Announcements
	9:30 AM		Pharma updates 3 @ 5 minutes

Agenda

Saturday cont'd

9:45 AM			Dr. John Mitchell – Growing up with MPS
10:10 AM			Dr. Kim McBride, Gene Therapy (Sanfillipo)
10:30 AM		Coffee Break	
10:45 AM			Dr. Beth Potter, The Canadian MPS Registry.
11:15 AM			Dr. Aneal Khan, Clinical Trials.
11:45 AM			SPEAKER PANEL - 4 Dr.'s
12:00 PM			Summarising Key Takeaways - Interactive Session with Mary Bone
12:30 PM		Graydon C	Lunch
1:30 PM			#1 - Breakout Session - Dr. Eva Mamak, Hospital for Sick Children - Youth Transition to Adulthood: Tips and Tricks
2:30 PM			Coffee Break
2:45 PM	4:00 PM		#2 – Breakout Session – Lisa Feitelberg, Hospital for Sick Children -The Heart of It All: The Importance of Caring for the Caregiver
4:00 PM		Hazel McCallion A	Children's Program PICKUP
6:00 PM	6:30 PM	Graydon Foyer	Mississauga School of Music 
6:30 PM	10:00 PM	Graydon C	Hearts Aglow Gala Dinner & Entertainment

Photo Upload Zone

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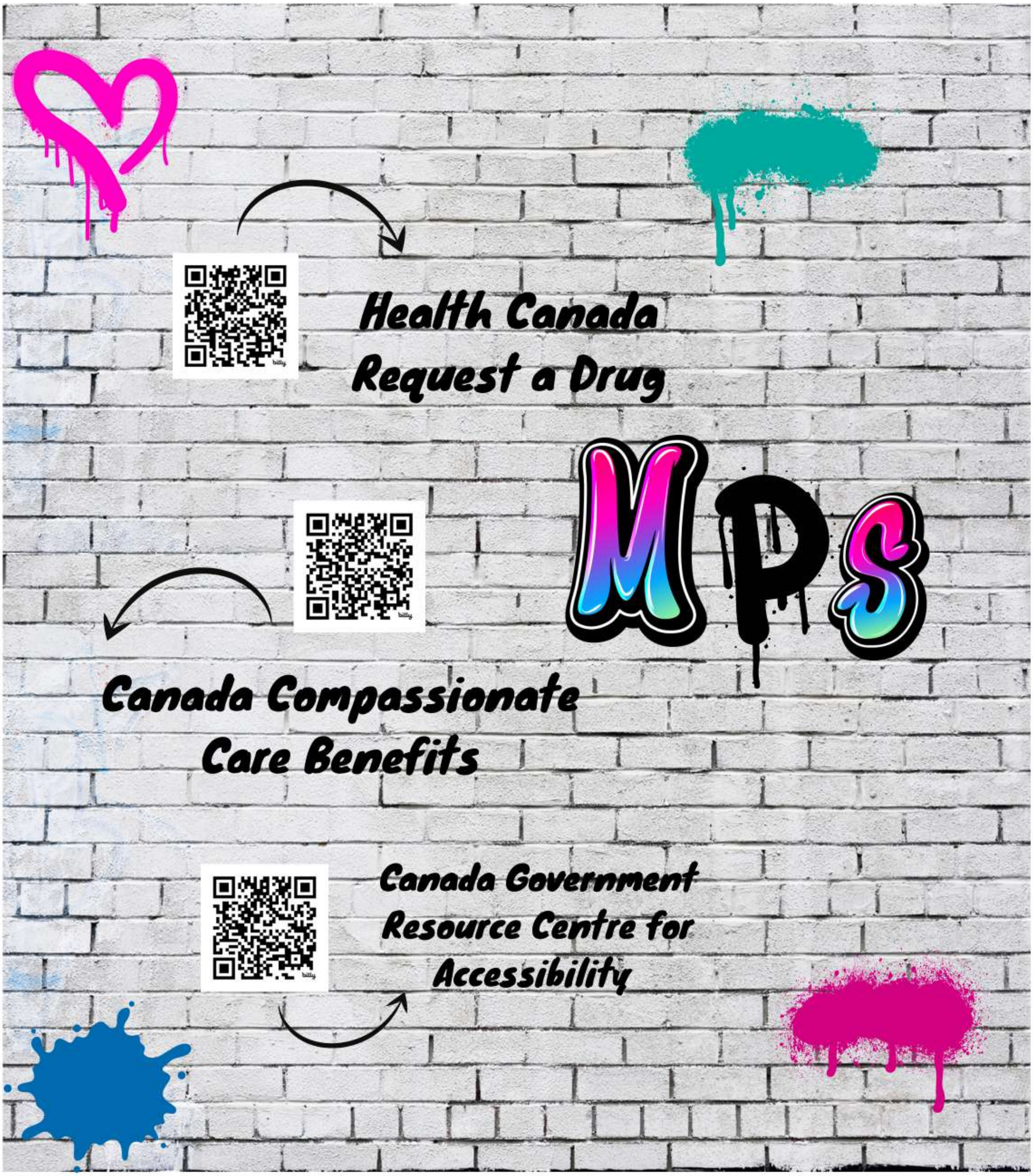
Agenda

Sunday, July 20, 2025			
6:30 am	8:45 am	Graydon C	Breakfast, buffet style
8:00 am	8:30 am		Children's program drop-off
9:00 am	9:30 am		Announcements
9:30 am	10:00		The ChangeMakers presentation, MPS Day, Nick Williams
10:00 am	10:30 am		Where do we grow from here, a look at how easily we can grow our connections using social media etc. Content needed, how to submit... Marilyn Marchment & Mary Bone
10:30 am	10:45 am	Coffee Break	Break
10:45 am	11:00 am		Annual Report Mary Bone
11:00 am	12:30 pm		AGM Call to order - Melissa Bilodeau, Chair Financials – Terry Byrne, Treasurer Vote on auditors Call for new board members. – Marilyn Marchment, Vice Chair Confirming the slate of board members, Julie Lariviere, Secretary Adjournment
12:30 pm		Boxed Lunches Graydon C	

Resource Wall



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