



Hemophilia Ontario Board of Directors Meeting

May 27th-28th, 2023

Hilton Toronto Airport Hotel

5875 Airport Road, Mississauga, ON

Participants	Attend	Regrets	Participants	Attend	Regrets
Emil Wijnker President & Chair	x		Cameron Peters Vice President	x	
Amy Griffith Secretary	x		Prakash Singh Treasurer	x	
Ash Kurichh Director	x		Raja Ammourey Director	x	
Peter Zhang Director	x		Terri-Lynn Langdon Director	x	
Megan Reid Director	x		Jordan Cabral (zoom) Board Youth Intern	x	
Byron James Executive Director	x		Susan Turner Manager – Admin. & Fund Development	x	
Natalie Philbert Manager – Women’s Services & Programs	x		Sarah Levy Manager – Member Services & Support	x	
Luke Chasse Staff – Camp Programs & Youth Leadership	x		Everton (Jamie) Caine Board Youth Intern	x	

Others in attendance:

Scott McElligott – Manulife Investments (Sunday Morning)

May 27, 9:00 AM – 4:00 PM

Agenda Item	Action Required		
	Information	Discussion	Decision
1. Call to order - Emil @ 9:10am			x
1.1 Quorum			x
1.2 Declaration of conflicts	x		
1.3 Approval of agenda <ul style="list-style-type: none"> Discussion to amend agenda as presented to update Operations Restructure from Saturday May 27 to Sunday 28. Novo Nordisk to present to board on Sunday May 28 from 12pm - 1pm as a working lunch <p>Motion: to approve agenda as amended</p> <ul style="list-style-type: none"> Move: Cam Seconded: Ash Carried 			x
2. Approval of previous meeting minutes – April 5, 2023			
Motion: to approve minutes as amended			
<ul style="list-style-type: none"> Move: Amy Seconded: Raja 			x



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<ul style="list-style-type: none"> ● Carried 			
<p>3. Board Orientation - Emil</p> <p>Action - Emil to send powerpoint to board members</p> <ul style="list-style-type: none"> ● Objectives ● Governance <ul style="list-style-type: none"> Discussed mindset in which decisions are being made at the board table ● Strategic Planning ● Mission and Vision - why they matter <ul style="list-style-type: none"> Comprehensive care ● Who we serve ● Question: Should the naming of our organization be reviewed? <ul style="list-style-type: none"> ○ discussion reviewed from the previous strategic planning process. Sarah Ford reviewing for CHS and NHS US also reviewing possible name change ● Question: Should inherited bleeding disorder be included in the description or not? How do we make this more clear to our community? (update to the mission and vision wording inherited to just bleeding disorder) <ul style="list-style-type: none"> ○ Discussion about Chapter Collaboration Council (CCC), previous twinning projects, twinning project through the CHS (Trinidad and Tobago) ● Question: Who determines or organizes twinning projects? WHS <ul style="list-style-type: none"> ○ Our responsibility to have outreach beyond Ontario on a National Level ● Question: What programs are in place to support Mental Health and Wellness? <ul style="list-style-type: none"> ○ Review during programs discussion ● Question: Website maintenance and check in? <ul style="list-style-type: none"> ○ Review and update happening weekly in sections. Time to do a complete review and update for the whole site. ● Strategic priorities 2022-2025 <ul style="list-style-type: none"> Eight priorities that are highlighted in strategic plan: <ul style="list-style-type: none"> Advocacy & Clinic Relations Building our Community Camps Communication Fund Development Governance Honouring our Legacy Women's Health 	<p>X</p>	<p>X</p>	



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<ul style="list-style-type: none"> ● Discussion to review updates and or make revisions to the strategic plan.To be discussed further Sunday May 28th. How we are tracking progress Balance Scorecard (excel) ● Budget and Action plan ● Roles of the Board Working board hybrid model ● Board Meetings ● Questions Which committees/working groups are in place? Finance, Governance Raja to join the FAC ● Quiz 			
Break: 10:15 – 10:30 AM			
<p>4. 2023-2024 Executive Committee Elections</p> <ul style="list-style-type: none"> ● Emil appointed Cameron as presiding chair for the election process. ● Proposed slate for 2023 - 2024 President - Emil Wijnker Vice President - Amy Griffith Treasurer - Prakash Singh Secretary - Megan Reid <p>In camera 11 am</p> <ul style="list-style-type: none"> ● Nomination for President - Emil 11 am -11:08 am ● Nomination for Vice President - Amy 11:08 am-11:15 am ● Nomination for Treasurer - Prakash 11:15 am - 11:24 am ● Nomination for Secretary - Megan 11:24 am - 11:30 am <p>Out of camera 11:30am</p> <p>Motion: <i>to appoint slate of roles as presented</i></p> <ul style="list-style-type: none"> ● Move: Cam ● Seconded: Peter ● Carried 		<p>X</p>	<p>X</p>



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<p>Cam moved the role of chair back to Emil</p> <p>Motion: to appoint Megan Reid as the Ontario Delegate to the CHS Chapter Collaboration Committee</p> <ul style="list-style-type: none"> ● Move: Amy ● Seconded: Raja ● Carried 			
<p>5. ED Report/Remarks - Byron</p> <ul style="list-style-type: none"> ● AGM community weekend <ul style="list-style-type: none"> Accolades to the staff! Session Ratings 155 attendees (31 Thunder Bay) Thunder Bay AGM: Feedback Session Question: How was the collaboration with CHS for the weekend? <ul style="list-style-type: none"> ■ Women’s Plenary was helpful in relationship building and supporting future endeavours with the WFH (Sarah Ford, Wendy Quinn) ■ Sarah is looking to heighten collaboration with provincial chapters in the future Question: What is the expected cost of the weekend? <ul style="list-style-type: none"> ■ \$90,000-\$110,000 final invoices not provided yet. Original budget was \$36,000. Due to location and partnership with CHS costs above original forecast. ■ Action: Staff to bring Prakash and the FAC the final invoice upon receipt. FAC to review and meet prior to the scheduled July meeting to review cash flow and determine the best option for payment of AGM and family weekend invoices. Cash flow discussion to take priority to devise strategy to better meet our accounting and cash flow needs and determine if withdrawals will need to be made to cover cash flow needs ■ Q1 earnings from investments will help to offset some of the cost ■ Review opportunity for In Kind donations of resources and supplies for future events Question: How often is HST recovered? <ul style="list-style-type: none"> ■ HST is recovered two times per year 	x		
<p>6. Staff reports by Natalie Philbert, Susan Turner, Sarah Levy, & Luke Chasse</p>	x		
<p>Lunch: 12:00 – 1:00 PM Working Lunch</p>			
<p>6. Staff reports (continued)</p> <ul style="list-style-type: none"> ● What have we done Thunder Bay 	➤ x		



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<ul style="list-style-type: none"> ● Question: How are we supporting the Northern Region? <ul style="list-style-type: none"> ■ Possible council model for NOR. It is important to have visual representation at the board level. ● Programs and Advocacy <ul style="list-style-type: none"> Youth Program Clinic Advocacy ● Organizational Reorganization <ul style="list-style-type: none"> ○ Looking at job functions of Camp Manager - further discussion to occur Sunday May 28th ○ Diversified Funding Portfolio - more support requested for resources as well as working board members. Requesting board members to approach Byron to support a Fund Development working group/task force (corporate giving program). Possible review of what is available through MOH outside of OAN. ● Camps <ul style="list-style-type: none"> ○ Geography ○ Attendance and capacity - how do we ensure we have maximum attendance for future camp events ● Thunder Bay Clinic Pilot <ul style="list-style-type: none"> ○ Vanessa Bouskill and Sick Kids team to provide maintenance appointment training program ○ Byron and Sarah to spend four days week of May 28th with the Thunder Bay Clinic team to review budget and timelines ○ Possible Video appointment opportunities for remote regions ○ Opportunity for Pharma to support these programs and train on PSP programs ● Member Services - Sarah <ul style="list-style-type: none"> ○ OChart and OAN involvement - submitted for first half of 2023 and funding confirmed for 2024 ○ Financial Assistance - 43 cases YTD, expected to be slightly above budget by EOY due to more complex cases and higher reimbursement requests <ul style="list-style-type: none"> ■ Takeaway: Looking to how we can expand this service for our members and how we can offer the supports (looking at a streamlined protocol for how our members apply and how we choose to support them.) Collaboration between social workers and educators to have longer term plans to support families. Look at donor engagement. ○ Special Cases review - previous motion to continue to provide support until November of 2023 for Sharam. Will ensure we work to ensure gradual transition of support for all special cases. ○ AGM Contributions - Kids programming, Gene Therapy, Thunder Bay Focus Group, Patient Support Session 			
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<ul style="list-style-type: none"> <ul style="list-style-type: none"> <ul style="list-style-type: none"> ■ Takeaway: Planning for more support with kids program (child to volunteer ratio), possibly board members to rotate to support with overseeing programming. Youth volunteer agenda. ■ Question: How are we engaging with Child welfare agencies? Jamie will reach out to Byron to support. ○ Programs - Prolonged Half Life Therapy Webinar, Peer support Orientation, Peer Support Network Launch ○ Upcoming programs - Gene Therapy Webinar, PSP event at upcoming Zoo Walk, Summer Event at Bingeman's, Summer event in Ottawa, possible Thunder Bay event, Camp Davern, Book Club launch (50+ age group and younger demographic, Trivia Nights for 19-30 male age group) ○ Mental Health resources - possibly a webinar ○ Continuing to work on priorities and then decide moving forward a working plan to bring new programs forward that are sustainable. I.e. Mental Health - tie-in with clinic advocacy and clinic support for social workers in every clinic - taking advantage of timing and appetite and climate to support ○ Looking at monthly spotlight on volunteer and or board member ○ Creation of a DEI calendar ○ A deep dive of Razor's edge will be conducted to drive donations. ○ Advocacy - Clinic Relationships, London Business Case - improved resources now available, template or master business case for all clinics to be prepared <ul style="list-style-type: none"> ■ Action: Sarah to reach back out to clinics with updated COVID protocols and determine if she can start attending in person again ● Camp Update - Luke <ul style="list-style-type: none"> ○ Community Camp (formally Pinecrest) ○ Youth Adventure and Mentorship Program <ul style="list-style-type: none"> ■ Action: possibility of hosting a youth engagement event from the 19-30 age group. Start with a small event and grow from there ○ Just the Dads ● Finance and Administration - Susan <ul style="list-style-type: none"> ○ AGM ○ John Plater Scholarship - 23 applicants vs 6 from previous year ○ Golf Tournaments - Shawn Durford taking place in Ottawa on July 8th (first time since 2014.) Hemophilia Golf Classic to take place September 22 at Bond Head Golf Club <ul style="list-style-type: none"> ■ On-line auction (Silents Auctions) to take place for both golf tournaments. Website will be live for one week allowing 			
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<p>additional access to bid on items. 25% of proceeds go to HO. 100% of proceeds for any items entered in auction by HO</p> <ul style="list-style-type: none"> ■ Can register for the dinner only ticket as well - requesting local board members to try to attend if possible ○ Zoo walk community event and fundraiser to take place June 24th ○ Nevada and Bingo <ul style="list-style-type: none"> ■ Susan and Bryon to meet with the City of Toronto to adjust our use of proceeds to expand what programs we can support in the city of Toronto with our bingo funds ● Women's Department - Natalie <ul style="list-style-type: none"> ○ Webinars <ul style="list-style-type: none"> ■ Mental Health July (anxiety), Care Giving (September), Gender (engage with organization), Aging (Pam Wilton) ○ Talk series <ul style="list-style-type: none"> ■ Adolescent (iron deficiency and Anemia), Amy and Vanessa, Wendy Quinn CHS) ○ Physician Assessment <ul style="list-style-type: none"> ■ Self Bat language to be updated to be inclusive of all that menstruate ■ QR code to help identify when a self bat should be taken ■ Mechanism to identify abnormal bleeding ■ Once package is created, it can be piloted in office (to be trained by Joel and Vanessa) ■ Period - what primary care providers should be looking for ○ Women's Plenary <ul style="list-style-type: none"> ■ Future Road Show - suggestions to go on the road for chapters. Working with Sarah Ford ■ Milena Pirnat, Dr.Pike, Pam Wilton - Heroixx presented for platform ○ Adolescent Session <ul style="list-style-type: none"> ■ Highest rated session ■ Anemia and Iron Deficiency ○ Heroixx Marketing <ul style="list-style-type: none"> ■ One Year Anniversary of Launch! Reviewing potential changes to the site and need for translation. ■ Canadian Women's Foundation. ■ Article - period poverty with Peter and Natalie to submit to the Globe or the Star. ○ What's coming up 			
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<ul style="list-style-type: none"> ■ Working with Hamilton Trans Health Coalition for possible talk ■ Caden to do an FAQ for Heroixx - with a disclaimer on current climate on why they want to remain anonymous. ■ Book Club fall launch ■ Possible talk at WFH Global Summit on Women and Girls with Bleeding disorders session in September to highlight Heroixx (if Canada is selected) ■ Review the possibility of operationalizing a project to see where we can go on period poverty once physician assessment is started. Federally mandated employers to offer free menstrual products ■ Identify revenue streams to support Heroixx into 2024 ■ Grant writing templates and overcoming the challenge of reserve funds. 			
Break: 2:45 – 3:00 PM			
7. Operations Restructure <ul style="list-style-type: none"> ● Moved to agenda for Sunday May 28th 	X	X	X
8. Scholarship report - Cam <ul style="list-style-type: none"> ● Discussion moved up from Sunday agenda <p>Motion: <i>to approve the Bursary and John Plater Scholarship award winners as recommended by Dr. Kristin Ciupa.</i></p> <ul style="list-style-type: none"> ● Move: Cam ● Seconded: Prakash ● Carried ● Question: Are funds disbursed to the award winner or educational institution? <ul style="list-style-type: none"> ○ Funds are disbursed to the educational institution. <ul style="list-style-type: none"> ■ Action: request assessor to present recommendations to the board for future bursary and scholarship award winners. ■ Action: revise the application process to include a date of decision for applicants. 		X	X
9. Parking lot items for the 28th <ul style="list-style-type: none"> ● Strategic plan ● Balance Scorecard ● Rotman discussion ● Gaps Analysis Report Patient needs 		X	X



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<ul style="list-style-type: none"> Meeting cost discussion ‘ Auditor RFP and legal by law review 			
10. Adjournment for the day @ 4:51 pm - Ash		X	X

Participants	Attend	Regrets	Participants	Attend	Regrets
Emil Wijnker President & Chair	X		Cameron Peters Director	X	
Amy Griffith Vice President	X		Ash Kurichh Director	X	
Prakash Singh Treasurer	X		Raja Ammourey Director	X	
Megan Reid Secretary (Zoom)	X		Terri-Lynn Langdon Director	X	
Byron James Executive Director	X		Jordan Cabral Board Youth Intern		X
Peter Zhang Director	X		Jaime Caine Board Youth Intern (joined @ 9:43)	X	
Scott McElligott Manulife Wealth Management Portfolio Manager (Investment Counsellor)					

May 28th, 9:00 AM – 2:00 PM

Agenda Item	Action Required		
	Information	Discussion	Decision
1. <u>Call to Order</u> - Emil @ 9:07 <ul style="list-style-type: none"> Quorum Declaration of Conflicts 			X
2. <u>Operations Restructuring</u> - Byron		X	X



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<ul style="list-style-type: none"> ● Discussion around staff roles (e.g., Camps, Social Media) now that we have recently had staffing changes ● Goal is continuity amongst roles and responsibilities ● Propose creating Coordinator of Camps and Events (full time position, not contract) at a coordinator salary level \$40-47K per year with benefits after three months ● Want someone with Raiser’s Edge background ● Byron to write business case and job description for approval with a goal to begin and hire in 2024 ● <i>Moved in Camera at 9:20 with Byron as an invited guest</i> ● <i>Moved out of Camera at 9:45</i> 			
<p>3. <u>Strategic Plan, Review and Update</u> - Peter, Emil</p> <ul style="list-style-type: none"> ● Action: Board to divide and review the Strategic Plan for presentation in summer <ul style="list-style-type: none"> ○ Advocacy and Clinic Relations: Cam, Terri-Lynn ○ Funds Development: Ash, Megan ○ Communications: Peter ○ Women's Health: Amy, Terri-Lynn ○ Building Community: Raja, Megan, Jaime ○ Governance: Cam, Prakash ○ Camps: Emil, Jordan ○ Legacy: Cam, Emil 	x	x	x
Break: 10:20 AM – 10:35 AM			
<p>4. <u>Investment Report</u> - Scott</p> <ul style="list-style-type: none"> ● Reviewed management process for new members ● Starting to see bond yields return to a normalized rate ● Interest rates at their highest rate in decades, however are starting to normalize ● Softening in returns globally, growth rate is positive ● Accelerated ESG Focus (Environmental, Social, Governance): it will become increasingly necessary to apply an ESG lens to standard investment calls (e.g., Budweiser LGBTQAI+ example) ● Question: Allow liquidity for Cash Flow in asset balance (currently 1%)? <ul style="list-style-type: none"> ○ Recommended and will be reviewed by Finance Committee and Byron/Marina ● Question: Calculating net loss on \$50K withdrawal in last quarter? <ul style="list-style-type: none"> ○ Action: Scott to create and sent to Cam ● Question: What is our reporting structure? <ul style="list-style-type: none"> ○ Monthly soft copies sent to Byron and Marina ○ Portal not being used by organization ○ Action: Cam to request copies also be sent to the Treasurer ● Question: Explanation on custody and signing authority <ul style="list-style-type: none"> ○ RBC is custodian to protect capital, portfolio managers must have a custodian. Manulife sends instructions to the custodian for any happenings in the portfolio (money in/out) ○ Recommended that there be two, updated signing authorities (currently Byron James and Daivd Neal) ○ Action: Cam to complete paperwork (with IDS of signing authorities) on DocuSign with Scott ● Question: What is ESG compliance for Manulife? (e.g., social justice considerations) 		x	x



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<ul style="list-style-type: none"> ○ Decided it was more important to protect our assets than make social justice considerations. ○ Action: Scott to send ESG philosophy ● Question: Are we comfortable with our 1% yields? <ul style="list-style-type: none"> ○ No, but we feel good about it with all considerations being made. We are looking at the 5-year horizon, we are getting close to the forecast return ○ Action: Scott to create 5 year projection graph for the board ● Question: What are our fees? <ul style="list-style-type: none"> ○ 1.45% quarterly fee, charged on the portfolio market value (tracked daily) which covers all third party money manager hiring, all investment trades, portfolio presentations, Scott's time (including philanthropy support) 			
Working Lunch with Novo-Nordisk: 12:00 PM – 1:00 PM			
<p>5. <u>Novo Nordisk Presentation</u></p> <p>* Amine Bouchakor Moussa (Product Manager), Edwin Chu (Field Medical Advisor)</p> <ul style="list-style-type: none"> ● Pipeline: Mim8 (Hemophilia A, all ages) and Alhemo (Hemophilia A, B and Inhibitors for 12+ years) ● Request to be involved in the launch timeline for new products in the event that advocating for funding and accessibility needs to be done (e.g., Hemlibra example) ● Expressed need for support and partnership: clinical trial updates and outreach to community (Hemophilia only), education on what trials are and how patients can participate, lack of awareness and participation - centers don't seem to be communication available trials well with patients 	x		
<p>6. <u>Board Meeting Calendar 2023-2024</u></p> <ul style="list-style-type: none"> ● Current practice has been to meet via Zoom at 6:30 PM on the 1st Wednesday of each month (except December with a one-week delay in January) ● Two in-person meetings over weekends over the course of the year: <ul style="list-style-type: none"> ○ Budget-setting: last weekend in November ○ Program planning: last weekend in May <ul style="list-style-type: none"> ■ Wednesday July 26th @ 6:30 PM via Zoom ■ Wednesday September 6th @ 6:30 PM via Zoom ■ Wednesday October 4th @ 6:30 PM via Zoom ■ Wednesday November 1st @ 6:30 PM via Zoom ■ November 25th-26th @ in-person Toronto ■ Wednesday January 10th @ 6:30 PM via Zoom ■ Wednesday February 7th @ 6:30 PM via Zoom ■ Wednesday March 6th @ 6:30 PM via Zoom ■ Wednesday April 3rd @ 6:30 PM via Zoom ■ Wednesday May 1st @ 6:30 PM via Zoom ■ May 25th-26th @ in-person Toronto ● Action: determine date for Pharma meetings in the Fall (2023) ● <u>2024 AGM Date & Location</u> <ul style="list-style-type: none"> ○ April 2024 <ul style="list-style-type: none"> ■ Proposed dates: 6th-7th, 13th-14th ○ Location: Nottawasaga, Kingston, Ottawa 	x	x	x
<p>7. <u>Other Business</u></p> <ul style="list-style-type: none"> ● Rotman School of Management 		x	x



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<ul style="list-style-type: none"> ○ Program has been an ongoing partnership for the last 4 years in the form of a Rotman fellow, to work on a Strategic Project (e.g., seeking funding, governance, strategic plan) ○ Program has been collapsed so this program is now a class rather than an experiential learning opportunity, meaning that students are not screened to the same caliber ○ Rotman is now directing what projects their students work on <ul style="list-style-type: none"> ■ “Social Impact Investing” - creating pitches, fund development ○ Two students this year rather than one, less support from Rotman due to personnel changes ○ Peter to be board lead at this time ● Gaps Analysis <ul style="list-style-type: none"> ○ Pfizer hired an outside consultant to identifying gaps in our community (e.g., programming, support) ○ Gaps in mentorship, self advocacy, community advocacy and personalized communication ○ Review Key Takeaways for new members ○ Action: to redistribute the Gaps Analysis Report to the board for review alongside the Strategic Plan ● Meeting Costs <ul style="list-style-type: none"> ○ Tabled to July 26th meeting ● Auditor RFP <ul style="list-style-type: none"> ○ Current cost is \$11K ○ Action: Byron to initiate the RFQ process with two outside auditors over 5 year cost projection ● By-Law Legal Review <ul style="list-style-type: none"> ○ Tabled to July 26th meeting 			
<p>8. <u>Signing Authority</u> - Cam</p> <p>Motion: <i>With respect to investments held by Manulife, with RBC acting as custodian of the funds, effective immediately: David Neal and Byron James are no longer signing authorities; and two people are required to sign off on transfers in to or out of Hemophilia Ontario’s investments held by Manulife. Signing authorities for Hemophilia Ontario’s investments held by Manulife are: Amy Griffith, Cameron Peters, Prakash Singh, Megan Reid.</i></p> <ul style="list-style-type: none"> ● Move: Ash ● Seconded: Peter ● Carried <p>Motion: <i>to increase the number of signatures from one to two, who can sign off on transfers into and/or out of Hemophilia Ontario investments held by Manulife</i></p> <ul style="list-style-type: none"> ● Move: Cam ● Seconded: Raja ● Carried 	x	x	x
<p>9. Adjournment @ 2:23 - Ash</p>			x



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