



Hemophilia Ontario Board of Directors Meeting

November 26 & 27, 2022

Fern Resort – Orillia, ON

November 26, 9:00 AM – 5:00 PM

Participants	Attend	Regrets	Participants	Attend	Regrets
Emil Wijnker Chair	X		Stefan Lubinski Youth Fellow		X
Cameron Peters Vice-Chair	X		Tiffany Oei Rotman MBA Fellow	X	
Prakash Singh Treasurer	X		Byron James Executive Director	X	
Amy Griffith Secretary	X		Susan Turner Manager of Administration & Fund Development	X	
Ash Kurichh Director (left @ 5:30)	X		Natalie Philbert Manager of Women's Programs & Services	X	
Megan Reid Director (joined @ 1:20)	X		Alexandra McGillivray Manager of Camps & Communications	X	
Brad Barbour Director		X	Sarah Levy Manager of Member Services & Support	X	
Peter Zhang Director	X		Sarah Crymble Hemophilia Provincial Coordinator	X	
Alexandria Aquino Director (Special Pick)	X		Mela Swayze Consultant – Equity, Diversity & Inclusion	X	

Agenda Item	Action Required		
	Information	Discussion	Decision
1. Call to order @ 9:20			X
1.1 Quorum			X
1.2 Declaration of conflicts	X		
1.3 Approval of Agenda Moved: Peter Seconded: Prakash <ul style="list-style-type: none"> Addition of In-camera session on Sunday Edit of Sarah Crymbe's name to "Hemophilia (not Nurse) Coordinator" Carried			X
2. Approval of previous meeting minutes – October 25 ** Edit: Rotman spelling (one T not 2) Motion: Amy Seconded: Prakash Carried			X
3. Website/social media analytics, Staff (9:57) <ul style="list-style-type: none"> Yielded increase in social media increase 	X	X	



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<ul style="list-style-type: none"> ● Average engagement rate is 1%, at 3-20% per post ● Doubled the percentage of our followers ● Now have colour scheme and social media kit ● More education posts (myths, difference between IBDs) ● Creation of LinkedIn page ● Ease on staff (less time on content creation) ● Mutually beneficial for students as they gain experience and get exposure ● Hiring new students for 2023 (has already been reviewed by Rav and posted) ● Website is getting audited for re-launch in January ● Pharma portal up (Roche and Octpharma engaged) 			
Break: 10:15 AM – 10:30 AM			
<p>4. Staff 2022 program presentations by Natalie Philbert, Susan Turner, Sarah Levey and Alex McGillivray (2:57)</p> <ul style="list-style-type: none"> ● <u>Susan Turner (Admin)</u> <ul style="list-style-type: none"> ○ BINGO is fully open and operational, two sessions per month @ \$3K-3.5K per month ○ \$20K of funding used for Wanakita and nursing ○ 26 Nevada locations, up 19 from 2021 - used \$92K for program expenses (camps, community weekend) and financial assistance ○ Golf tournament raised \$16K, tournament moved to Bond Head golf club in 2023 - many courses want a flat rate regardless of number of golfers (reason for move) ○ 48 attendees at the Zoo Walk, raised \$2.3K ○ Working on having all staff trained on Raiser's Edge (target monthly donor increases) ● <u>Sarah Levy (Member Support and Services)</u> <ul style="list-style-type: none"> ○ 7% increase in member/financial support cases, 87 individual served ○ seeing individuals back for multitude of financial assistance - fewer new members but higher financial need ○ Physio/massage, prescription medications and Medic Alert are most reported. Transportation/parking are also high ○ 4 different immigration cases ongoing (with lawyer) ○ Launch of new Member Support Program, 3 new families attended, extremely well received - next event December ○ OCHART has been submitted ○ Placement student (Larisa), social services at Seneca - working in reaching out to eligible families ○ <u>Shahram update</u>: mental health is low (lonely, missing family and worried about the state of Iran). Needs elbow surgery, having pain management issues. Want to be sure how any form of income would impact his ODSP eligibility. Looking for a work from home option. Looking to help him get engaged in the community in a way he can (volunteer) 	X	X	



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<ul style="list-style-type: none"> ○ Improving data collection through Financial Assistance and Membership Applications ○ Development of Member Support Guide to be used as a physical resource in physicians office and at clinics ○ 4 educational Webinars (ideally 1 per quarter), continue to publish Monthly Clinic Update ○ Development of business cases for all Ontario clinics for incremental human resources increases at clinics ● <u>Alex McGillivray (Manager of Camps)</u> <ul style="list-style-type: none"> ○ Wanakita: 42 campers, 77 infusions <ul style="list-style-type: none"> ■ 2023: 48 campers registered, 17 remaining ○ Pinecrest: 18 campers, 11 infusions <ul style="list-style-type: none"> ■ Issues with site, moving to a new location in 2023 and date (August-September) ○ Just the Dads: <ul style="list-style-type: none"> ■ 53 participants, 4 youth volunteers, 3 presentations ○ Youth Adventures + Mentorship Pilot Program: <ul style="list-style-type: none"> ■ Ages 14-18 (matching with camp programming), minimum 12, maximum 20 participants ■ HOY with new mentorship piece with a “giving back” objective ■ Acts as succession planning for the organization ■ 3 events per year <ul style="list-style-type: none"> ● 1st Winter 2023 (Feb at Wanakita) ● 2nd City Trip ● 3rd Fall Event in outdoor setting ● <u>Natalie Philbert (Manager of Women’s Services)</u> <ul style="list-style-type: none"> ○ <i>Moved to end of day</i> 			
Lunch: 12:00 PM – 1:00 PM (1:20)			
<p>4. Hemophilia Provincial Coordinator presentation, Sarah Crymble (2:04)</p> <ul style="list-style-type: none"> ● Advocacy <ul style="list-style-type: none"> ○ Monitoring clinic staffing ○ National Standards of Care review - Ontario Self Assessment ○ Ensure seamless transition to adult care ○ Provide education and resources for clinics ● Camps <ul style="list-style-type: none"> ○ Standardization of medical directives and treatment guidelines (across all camps) ○ Development of camper education booklet ○ Development of a Youth Leadership Program through SC program at Wanakita ● Women’s Health <ul style="list-style-type: none"> ○ GP knowledge dissemination initiative ○ Local Symposium for non Treatment Centre Staff - invite staff from surrounding HTC hospitals (physio, ER, social work) 	<p>X</p>	<p>X</p>	<p>X</p>



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<ul style="list-style-type: none"> ○ Enhance resource development - needs assessment on anemia resource 			
Break: 2:45 PM – 3:00 PM			
<p>5. Diversity & Equity presenter Mela Swayze (5:14)</p> <ul style="list-style-type: none"> ● Identified areas of inequity: age, gender, history (HIV), geography, standards of care and it's distribution amongst clinics ● Identified importance of EDI: to be more aware of our biases and lenses, to be more aware of our community and gaps, to be more aware of the harm we can cause, to be more aware of our visibility, to be more aware of how we can earn the trust of the members of our community, drawing others in to a safer space ● Gaps: partnerships with outside organizations, safe space communication, more meaningful and diverse partnerships, ● Committed steps: succession planning, women's care, LGBTQ2S+ relationships, allyship and protected spaces 			
<p>6. Items for discussion, Adjourn (6:14)</p> <ul style="list-style-type: none"> ● <u>Natalie Philbert (Manager of Women's Services)</u> <ul style="list-style-type: none"> ○ Heroixx metrics (overview): ○ 5 education webinars, 4 episodes on The Flow talk series (yearly goal is 5 episodes) ○ Stakeholders: <ul style="list-style-type: none"> ■ Octapharma - working with Rama al Tout ■ VWD patient study in Canada ■ Dr. Pike - Pediatric Hematology-Oncology Fellow ■ Dr. Blackman - Hematologist (East Coast) ■ Dr. James - letter of support ■ Dr. James/Scholzberg - co-authorship on Heroixx/research (physician assessment) ○ 2 in-person sessions at AGM ○ Pots and Wreaths: smaller income due to pricing, but value in community event (not a fundraiser) ○ Physician Assessment Strategy: <ul style="list-style-type: none"> ■ Goal to reduce delay in diagnosis ■ Working on a tool which doctors can use to determine wavy menstrual bleeding and generate a referral ● Adjournment @ 6:30 	X	X	



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November 27, 9:00 AM – 2:00 PM

Participants	Attend	Regrets	Participants	Attend	Regrets
Emil Wijnker Chair	X		Alexandria Aquino Director (Special Pick)	X	
Cameron Peters Vice-Chair	X		Stefan Lubinski Youth Fellow		X
Prakash Singh Treasurer	X		Tiffany Oei Rotman MBA Fellow	X	
Amy Griffith Secretary	X		Byron James Executive Director	X	
Ash Kurichh Director	X		Susan Turner Manager of Administration & Fund Development	X	
Megan Reid Director		X	Natalie Philbert Manager of Women's Programs & Services	X	
Brad Barbour Director		X	Alexandra McGillivray Manager of Camps & Communications	X	
Peter Zhang Director	X		Sarah Levy Manager of Member Services & Support	X	

Agenda Item	Action Required		
	Information	Discussion	Decision
1. Call to order @ 9:13			X
1.1 Quorum			X
1.2 Declaration of conflicts	X		
2. Parking lot items from the 27th (11:00)			
<ul style="list-style-type: none"> ● <u>Motion re: Financial Support for Shahram (Exceptional Case)</u> <ul style="list-style-type: none"> ○ Rent amount has not changed, ask is for \$750/month (\$9K a year) ○ Discussion continued from Saturday re: Shahram's current health and physical limitations, his desire to become more independent, and the scope of his ability. ○ Discussion around due diligence and establishing timelines for ongoing funding, while ensuring Shahram is supported ○ Motion: Cam <ul style="list-style-type: none"> ■ To approve the request for exceptional support for SB such support not to exceed \$9,000 CDN conditional on rent receipts by SB. Support will be up to November 30, 2023. Payments to be made directly to the landlord to Hemophilia Ontario. ○ Seconded: Prakash ○ Carried ● <u>Clinic Advocacy Campaign</u> <ul style="list-style-type: none"> ○ To create a working Advocacy Committee with Sarah Levy as staff support (Cam, Alex) "Committee of the Board" ○ Tracy Lindsay to develop advocacy campaign and reports alongside the committee, \$10K budget line to support 		X	X



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<ul style="list-style-type: none"> ○ Motion: Cam <ul style="list-style-type: none"> ■ To strike a committee of the board called the Clinic Advocacy Take Force ○ Seconded: Peter ○ Carried ● <u>OneDrive</u> <ul style="list-style-type: none"> ○ Development of Board shared OneDrive folder for simultaneously sharing and editing ○ Staff to create, all board members to have access ● <u>Gene Therapy Update</u> <ul style="list-style-type: none"> ○ Factor 9 been approved at \$3M+ ○ Concern that our membership believes that gene therapy is a “cure” of Hemophilia. CHS developing documents and resources to better educate members, we will be responsible for supporting it’s distribution ○ PSP Webinar to support members accessing through the website ○ EHL Webinar happening in December with Dr. Chan and Vanessa Buskill ● <u>Strategic Plan Metrics</u> <ul style="list-style-type: none"> ○ Create a stoplight document for getting Strategic Plan updates, quarterly. First to be in January 2023 ○ Some board members asked for action reminders when items that pertain to their involvement approach ● <u>Product Safety Statement of Principles re: Grifols</u> <ul style="list-style-type: none"> ○ Discussion around how to address the current paid plasma deal, through education, our stance, our principles, etc. ○ Question on whether we align with and defer to the CHS position which was released in October ○ Proposed that we create an FAQ with more information for members ○ <i>Tabled until January 2023</i> 			
Break: 10:20 AM – 10:35 AM			
<p>3. 2022 Budget presentation and approval (2:58)</p> <ul style="list-style-type: none"> ● Ongoing application of grants (Trillium, Mississauga, MoH, City of Toronto) ● Discussed all grant applications amongst staff, and that for some our reserve funds are a barrier to being accepted ● Parma relationships are accounted for, Takeda is only unknown (new person in role) to fund Camps, Women's programming and the AGM ● Byron to have conversation with Peter re: outside Pharms we are not currently engaged with (e.g, BioMarin, CSL Behring) ● Making distinguishable difference between program revenue and fundraising revenue moving forward ● Byron and Prakash creating a new accounting system (December) ● Discussion around Wanakita fees (currently \$200) to a by week structure. Decided to stay status quo to recoup from the pandemic, and add an optional donation option at the time of registration (too late for Wanakita this year, will add to Pinecrest). Intention to add to all events moving forward 		X	X



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<ul style="list-style-type: none"> ● 2% increase in staff salaries ● PROGRAM EXPENSES <ul style="list-style-type: none"> ○ <u>Community Camp</u>: many costs will be covered by CHS as we are combining with Rendez-Vous, members will pay an AGM fee on top of their registration fee for the event ○ <u>Wanakita/Pinecrest</u>: projected based on potential maximum capacity per camp (top scale) ○ <u>Women’s Programming</u>: discussion surrounding revenue outside of Pharma (even though Pharma is heavily engaged) ○ Removal of leased equipment fee from expenses (office shut down) ○ Discussion around returning to making a donation to HRMDC at CHS - there is some concern surrounding accounting. Cam to follow up for more information ○ Increase in staff training to accommodate more EDI training ● Moved: Prakash ● Seconded: Cam ● Carried 			
Lunch: 12:00 PM – 1:00 PM			
<p>4. New business for 2023</p> <ul style="list-style-type: none"> ● Board Meeting Schedule 2023: <ul style="list-style-type: none"> ○ Next meeting Wednesday January 11th, 2023 ● The board moved in camera @ 3:12 <ul style="list-style-type: none"> ○ <i>Tiffany Oei as an invited guest</i> ● The board moved out of camera @ 3:53 ● Moved: We approve an additional \$2,500.00 for each staff member for a job well done in 2022 <ul style="list-style-type: none"> ○ Motion: Peter ○ Seconded: Cam ○ Carried ● Rendez-Vous ● Board Governance Policy ● Organizational Priorities for 2023 and beyond ● Board assessment who is handling it ● AGM awards <ul style="list-style-type: none"> ○ <i>All above tabled to January</i> 		X	X
<p>5. Adjournment @ 3:57 Moved: Cam</p>			X