

January 2026 Board Meeting Minutes

Meeting/Project Name:	Jan 2026 The CureMAPK8IP3 Foundation Board Meeting		
Date of Meeting:	01/17/26	Start time:	2:30pm Eastern
Location:	Zoom	End time:	
Chair:	Anne Jones	Minute taker:	
1. Meeting Objective(s)			
Icebreaker, approval of November minutes and new director, president and treasurer reports, approve annual return, strategizing for rare disease month			
2. Attendance			
Present			Apologies
Marie Harris			Mariyana
Diane Carr			Ashley
Anne Jones			Haley
			Calyssa
3. Agenda, Decisions, Issues			
Topic/ Discussion notes			Discussion led by

1. Roll Call
2. Call to Order—not enough present for quorum so voting will be done via email/google forms
3. **Action Item:** vote to approve November 2025 meeting minutes
4. Team building goal this year: Icebreaker: What is one thing that makes the holidays for you?
5. President update:
 - a. **Action Item:** vote to approve filing 990N (postcard): we should meet the eligibility requirements for the year
 - b. Scientific advisory board meeting—meeting to be held early February
 - i. Members: Dr. Holzbaur (Penn U), Dr. Andrew Carter (Cambridge, UK), Dr. Christopher Quinn (UW-Milwaukee), Dr. Drerup (UW-Madison)—if available, Alexa, Dr. Brooks (parent, neurologist), Marie Harris (director, parent), Dr. Acosta-Baena (researched JIP4)
 - ii. Will also invite Amy McCooe to sit in—
 - Need to meet ahead of time with her
 - Marie suggested we should have a standing meeting with her
 - iii. Also inviting Dr. Gowrishankar
 - c. Trying to connect with Lisa Costen from DYNC1H1 [gene.org](#)
 - d. Will be re-registering charity in Delaware, SC, OK?
 - e. Simons Searchlight—filled out form, waiting for them to review (<https://www.simonssearchlight.org/>)
 - f. RTW Foundation—invited to apply for grant cycle, will work with Dr. Crowder and also check in with Dr. Gowrishankar; also meet with Amy McCooe to complement their research
 - i. Deadline 1st week of March, funds go out in mid April
 - ii. \$75-100K
 - iii. Marie to help
 - iv. Genetic landscape report
6. Treasurer Report:
 - a. Treasurer report (review of financials)
 - Revenue: 4th Quarter: 1430 (see #1), \$2230 total for 2025
 1. Every Gene has a story campaign (set aside for research): \$1,430 —Do we want to donate this to Dr. Chung right away or wait till after rare disease month?—wait till after
 - Expenses: \$763.08 for 4th quarter, \$1204.52 total for 2025
 - b. Bank account balance: \$2,100.49 (research: \$1,430 so \$670.49 for expenses)
 - c. \$5K donated—do we want to try to go for uplifting athletes grant by doubling it—yes
 - d. Annual report for 2025
 - e. **Action Item:** vote to approve annual filing for SC (information will also be used to file in OK) for charity registration
 - f. **Action Item:** vote to approve 2026 Budget
 - Send out another email with survey
 - Plan to help assist with food
 - Anne to reach out to Lisa Kaufmann about housing options and food options
7. Fundraising/Rare Disease Month Ideas
 - a. Ideas to promote rare disease month awareness? (will need help with this—volunteers?)
 - Write CNBC cures
 - Newsletter to donors
 - Recurring donors esp. With 29 for 29 recurring or others
 - b. Virtual challenge option? (<https://www.theconqueror.events/>) Do we want to do another 29 for 29 campaign?—virtual walk challenge
 - c. Campaign: Every gene has a story. Help us tell it. <https://givebutter.com/0clwJl>
 - Goal list for financially: Anne suggested funding in-person assessments for Natural History Study \$10,500=goal, would fund another 6 families for in person assessments for Boston
 - d. Also, will need to raise some funds for maintenance throughout the year
8. Conference
 - a. Group ideas: duck tours, harbour tours, behind 2 Brookline there is a puppet theatre for little kids
 - b. Anne to reach out about reserving a conference room
 - c. Time out Market—
 - d. Anne to ask Kelsey at Hilton Garden Inn about group dinner and conference room at the hotel

Anne

Anne

Anne/Marie

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Voting done virtually due to no quorum present link to voting results:			
 Board voting 2026 January board meeting (Responses)			
4. Action Items			
Action	Responsible		Due Date
Next Meeting			
	March 2026	Time:	2:30 pm EST
		Location:	Virtual

Meeting Summary notes:

Quick recap

The meeting began with an icebreaker about holiday traditions before transitioning to planning for their first scientific advisory board meeting in February. The group explored various research collaborations and initiatives, including potential partnerships with the Wolverine Foundation and discussions about genetic research projects. They concluded by reviewing their budget and fundraising strategies, including plans for an upcoming conference in Boston and exploring new fundraising tools like virtual challenges.

Summary

Voting Plans

Anne mentioned that some members couldn't attend the meeting due to various reasons, but they would proceed with voting on certain items via email if needed. Holiday tradition icebreaker question.

Scientific Advisory Board Planning Meeting

They then reviewed plans for their first scientific advisory board meeting scheduled for February 6th, which will include researchers studying molecular motors, UNC-16 gene homolog to MAPK8IP3 function in roundworms, JIP4 and the intersection of neurodegeneration and neurodevelopmental disorders. Marie reported that Dr. Lerner, who studies dopamine circuits, expressed interest in joining the board and requested a follow-up call to discuss her potential involvement.

Research Collaborations and Grant Opportunities

The group discussed potential collaborations and research initiatives. They agreed to meet with a researcher to discuss dopamine pathways, even if she doesn't join their team. They also plan to connect with Lisa Koston from the DYNC1H1 group to explore a research consortium. The team was invited to apply for RTW grants, with a deadline in early March and potential funding of up to \$100,000. They will meet with Dr. Crowder to discuss project proposals for the grant application on Jan 30..

Gene Therapy Collaboration and Research

The group discussed collaboration opportunities with the Wolverine Foundation, particularly regarding research projects and grant writing support from Marie, who offered her expertise in this area despite being on leave. They explored questions about up-regulating wild-type genes and the challenges of gene therapy due to size limitations, with The mentioning the need to investigate options like splitting genes or truncating them to smaller sizes. The discussion also touched on a new genetic landscape report being conducted by a new hire at RTW, which could help identify knowledge gaps and research opportunities for their MAPK8IP3.

Budget Review

They reviewed their 2025 budget, noting \$2,230 in donations and \$1,204.52 in expenses, with \$1,430 set aside for the natural history study. A new \$5,000 donation was received, and they considered using it for either the natural history study or raising another \$5K to be eligible for a matching grant from Uplifting Athletes to fund another researcher (which

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Date: _____

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was the preferred option). They reviewed the annual report and budget for the upcoming year, which includes plans for a conference.

Rare Disease Fundraising Strategies

The board discussed fundraising strategies, including exploring recurring donations. The group agreed to focus on fundraising for research during Rare Disease Month and considered ways to engage donors, such as sending newsletters and sharing stories with CNBC Cures. The group discussed organizing a walking challenge for families, with options to either participate in a "29 for 29" challenge or complete a virtual walking route. They explored the possibility of using a commercial platform that offers various walking routes, including a Boston-specific option like the Freedom Trail, though the cost was noted to be around \$34 plus \$63 for additional apparel. Diane expressed support for the idea and while Marie suggested it could serve as a promotional activity for an upcoming conference in Boston. The group agreed to further explore the options and potentially implement both challenges. The virtual challenge is

<https://www.theconqueror.events/>

Boston Conference Planning Discussion

Diane and Marie discussed planning the upcoming in-person conference in Boston, focusing on activities and dining options. They considered options like trolley tours, harbor cruises, and a puppet theater for entertainment, while exploring the possibility of using the Timeout Market for group dining. Marie offered to research local options and collaborate with Diane on planning. They explored the possibility of holding presentations and activities at the hotel to keep everything centralized. Anne mentioned reaching out to Boston Children's for potential restaurant recommendations and conference room reservations as well as reaching out to Hilton Garden inn to explore conference room options and food possibilities there. Marie offered to look into local resources and potential sponsors for the conference.

Conference Planning and Grant Opportunities

They also discussed a grant opportunity from RTW for rare disease research, with RTW providing details on the application process and requirements. Marie agreed to help Anne review the grant information and consider potential research partners. The conversation concluded with a brief discussion about fundraising challenges and the possibility of finding volunteers to help with various tasks.