

## May Board Minutes

<b>Meeting/Project Name:</b>	May 2025 The CureMAPK8IP3 Foundation Board Meeting		
<b>Date of Meeting:</b>	5/17/25	<b>Start time:</b>	2:30pm Eastern
<b>Location:</b>	Zoom	<b>End time:</b>	pm Eastern
<b>Chair:</b>	Anne Jones	<b>Minute taker:</b>	Ashley Hasty
<b>1. Meeting Objective(s)</b>			
Approval of new board member, report on SC Annual Report filing, Conference planning, research meeting with RTW and UAB update, summer fundraising strategizing			
<b>2. Attendance</b>			
<b>Present</b>			<b>Apologies</b>
Mariyana Hristova	Calyssa Pine	Anne Jones	Diane Carr
Ashley Hasty			Tracie Dauwe
			Haley Kinley
<b>3. Agenda, Decisions, Issues</b>			
<b>Topic/ Discussion notes</b>			<b>Discussion led by</b>

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1. Roll Call
2. Call to Order
3. **Action Item: vote to approve March 2025 Minutes (approved-see below)**
4. Introduce new board member: Tracie Dauwe
5. **Action Item: vote to approve Tracie as new member of board of directors (approved-see below)**
6. President update:
  - a. Filed SC Annual registration 4/30
  - b. Accepted to be part of Global Genes, Simons Searchlight-need to followup, Genetic and Rare Diseases Information Center at NIH National Center for Advancing Translational Science- rejected, may need to update website-Tracie going to ask your help on this
  - c. Grant update-meeting with RTW Foundation and UAB
  - d. We need to start a medical advisory team-Tracie would you be willing to be part of it once it is set up? This would be an annual or biannual meeting.
  - e. Read up on ICD-10 roadmap—we are not ready for this yet but Dr. Chung will help us when we are ready
  - f. Registering with citizens health group-do we want to do this?  
<https://www.citizen.health/>
  - g. Summer social circle dates to be by language as interest allows
  - h. need blurb and picture for website from Calyssa, Tracie
7. Treasurer Report:
  - a. Treasurer report (review of financials)
    - i. \$250 deposited, \$25 paid out for quarter 1
  - b. Bank account balance: 1658.16 as of 5/16
  - c. Zoom expenses coming up:
    - Do we want to keep zoom translations? (\$50 annually)
    - Looking into changing to nonprofit for zoom account, will hopefully get a discount on zoom expense
8. Virtual conference for 2025 November 8-9?
  - a. What speakers/topics would we want to have?
    - i. have invited: Dr. Chung/Alexa (confirmed)--what does an uncertain variant mean and how do they know if they got accepted into NHS?, Amy McCooe, UAB-Dr. Crowder
    - ii. Family connection idea: Show and Tell share what has helped you
    - iii. Have also reached out to n-Lorem and RTW Foundation to see if they want to present
    - iv. Diane--reading presentation?
    - v. Other ideas you have?
9. Summer fundraising
  - a. Ideas?
  - b. Anne/Haley to put together a fundraising packet for families
10. Next meeting: July 19th 2:30 Eastern
11. **Action Item: adjournment- (approved-see below)**

Anne

Calyssa

Anne

Anne

Action items voted on virtually over google form by board members. All motions passed with 4 ayes.

#### 4. Action Items

Action	Responsible	Due Date
Anne: update website, zoom, summer social circle dates, putting together conference schedule, work on fundraising packet, reach out to family re: Zoom		

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<p>Haley: help with promo flyer</p> <p>Tracie: help with updating website on MAPK8IP3 and research, get blurb/picture to Anne</p> <p>Diane: would you present on reading strategies at our virtual conference?</p> <p>Mariyana-help with RTW Foundation meetings as able</p> <p>Ashley-help with resource for next newsletter–how to explain MAPK8IP3 to classmates?</p> <p>Calyssa- get blurb/picture to Anne</p>			
<b>5. Next Meeting</b>			
<b>Date:</b>	April 27th 2024	<b>Time:</b>	2pm EST
<b>Location:</b>	Virtual		
<b>Objective(s):</b>			