

SYNGAP RESEARCH FUND

Collaboration. Transparency. Urgency.

**MINUTES
OF THE
ANNUAL MEETING
OF THE
BOARD OF DIRECTORS
OF
SYNGAP RESEARCH FUND, INCORPORATED**

December 31st, 2019

- Board met at 5 pm local time as planned. The meeting was called to order by Ashley Evans, Chair.
- **Roll call:** Evans & Graglia were in Half Moon Bay and Randazzo joined via phone from his home in the East Bay.
- **Previous minutes:** The board unanimously agreed that minutes for the previous board meeting were accurate and approved them as such.
- **Changing the board**
 - **Ashley resigns.** The board discussed that as 2019 has been productive and successful SRF should evolve from the current small board to a group of parent leaders. They agreed that to this end we should identify a cohort of leaders to replace the current board in Q1 2020. They also discussed that only one partner in a marriage should be on a board. With this in mind, Ashley resigned from the board effective 1/1/2020. She noted her ongoing commitment to SRF, specifically to support fundraising. Fil and Mike thanked her for her service.
 - **Rebecca to join the board and become the treasurer.** Mike nominated Rebecca to replace Ashley as the third member of the board until the larger board was convened. He noted her long service to the SynGAP community and financial acumen through her professional work. The board agreed unanimously.
- **Board evolution**
 - **Target size of the board.** There was agreement that the board should aim for 10 or more members, all parents and that they should be people who have demonstrated some commitment to SRF and bandwidth to support the organization in spite of their professional and personal obligations.
 - **Ambassador Program.** The board noted that the Ambassador program had grown under Virginie's leadership and is performing an important service for the community.

- **Emerging Leaders.** Board discussed key leaders who were surfacing and agreed they should be invited to the next iteration.
- **Scientific Progress**
 - **Progress reports have been submitted** by Scripps and Baylor, they are attached. Pending no objection from the SAB, the Board approved making the second scheduled payment for these grants.
 - **Progress reports have been requested** from Hopkins.
 - **Mike requested funding for two projects:**
 - First an **Organoid project with USC**, the request for support is attached, but essentially it was ~\$50,000 which would be matched by USC for an MEA for the Coba lab to gather data from SynGAP Organoids. The board approved funding this on the condition that at least half of the \$50,000 was raised from the SynGAP community.
 - Second, an assessment of how to pursue **Biomarkers for SynGAP**. SRF has retained the services of a consultant who was referred by Dr. M. Urdea who was suggested by Fil. The Board approved up to \$20,000 for phase one.
 - **Upcoming Collaborations**
 - **RareX.** Mike reported on RareX and indicated that when this ambitious project was off the ground, SRF was hopeful that they will be able to partner to ensure that SynGAP is included in the first wave.
 - **Colorado DEE Grant.** Mike reported that the CDKL5 foundation has approached SRF about supported a DEE Clinical Fellowship under Dr. Scott Demarest in Colorado. The idea is that immediately we help develop a general DEE clinic model, but also we learn to collaborate with other significant rare disease groups. The board approved the effort at the \$10,000 level in the first year.
 - **REN.** Mike reported that REN is undergoing a transformation and that SRF will engage. The board supported this and asked which other partnerships may be helpful. The team discussed a new effort called Combined Brain which Mike will further explore.
- **CZI.** Mike reported that SRF had made it into the final rounds and had submitted a substantial package, but that the decisions had not yet been reported.
- **2020 Outlook**
 - Mike reported that the **two events SRF was sure to attend in 2020** were AES & Global Genes. But he noted there were also a number of Rare Disease events in 2020 that he expected to take part in. The board agreed that we should recruit as many other parents as possible to join at these events so as to cultivate a strong cohort of patient leaders.
 - There are **three other events that SRF is considering but are not yet final:** A fundraising Gala, work with CZI if selected and the FDA meeting currently being led by another group.
- **Financial Outlook**
 - **Donations.** Mike reported that 2019 donations came in at \$376,574. He pointed out that Rebecca had not yet reviewed 2019 financials so we should not consider these numbers final. When asked about the number of donors, he pointed out that this was not easy to answer since donations which came through

Facebook and Paypal were aggregated and then passed on in aggregates each month. He indicated that this analysis would be done in 2020.

- **Major donors.** When asked about major donors the YTD Donations, Mike reported that he could only report on direction donations at this time: one major donor who gave \$250,000, another who gave \$20,000, the founders gave \$21,000 directly but also through various Facebook matches -- again their totals will need to be calculated -- and another donor gave \$5,000.
- **Obligations.** Going into 2020 Mike observed that SRF should expect to pay \$361,833 in existing commitments, as well as the \$55,000 agreed to in the board meeting. Additionally the founder have committed to cover all overhead costs. This suggests that SRF will need to raise at least \$45,000 just to break even in 2020.
- **Fundraising.** Mike mentioned that the Development Director, Peter Halliburton was working on a fundraising plan and that SRF was also looking forward to participating in a bike ride fundraiser with UPenn in mid 2020.

- **AOB**

- Mike shared that he will be resigning from his full time job in 1Q20 to devote more time to SRF.