

## **Raynor Cerebellum Project**

### **Background Information and Guide for Future Applications**

#### **The Mission:**

- **Improving the lives of those with Cerebellar Disease in seven to ten years.**
- To fund truly new research initiatives --- not simply a continuation or extension of labs' current research programs. Investigators must be able to explicitly "connect the dots" from what they propose to RCP's strategic goal.
- To fund well-reasoned endeavors that are too risky for traditional funding agencies because they may lack preliminary data, contradict dogma, or propose unprecedented technical ideas. These are the ideas you are actually nervous about sharing because they are so outrageously ambitious.
- To create a new research culture with collaborations between labs at multiple institutions and across multiple disciplines... "collaboration" instead of "competition"
- There will be entirely new mechanisms for acquiring funding, accountability and reporting. Needless paperwork will be discarded. To paraphrase the late Ross Perot, "When you see a snake --- just kill it, don't form a committee on snakes."
- The RCP governing board will work alongside researchers and clinicians at all steps of every project, sharing expertise and skill sets *in-person* to cross-fertilize existing ideas and improve and troubleshoot to generate unexpected new directions.
- This is an experiment in "goal-oriented science." Success is defined by whether we improve patients' lives, without necessarily knowing why therapies are working in the time frame we have set. The "why" can (and should) come later.
- Teams must be selfless in a singular pursuit of the common goal.

#### **What We Are Not:**

- We are not another funding source akin to the NIH.
- We are not doing research for the sake of only learning more about the cerebellum nor knowledge for the sake of knowledge. While that is a worthy endeavor, we are seeking a more direct link between the research we fund and the end goal of seeing a noticeable difference in patients' lives within 7 to 10 years.
- We are not seeking to fund researcher whose primary purpose is publishing, obtaining tenure, supporting a lab, speaking at conferences, or obtaining additional grants. These outcomes should be logical byproducts of a focus on our primary goal --- improving patients' lives in seven to ten years.
- We are not funding siloed laboratories that optimize their own positions over deeply collaborative work that integrates across fields.

## The Vision – A Man on the Moon

- We liken our goal to putting a man on the moon --- improving the lives of cerebellar patients within seven to ten years. Our success will require the collaboration across multiple specialties, across departments, across institutions, across oceans which will include cerebellar experts, neurosurgeons, clinicians, basic scientists, imaging experts, data scientists, and technologists and a host of other specialties using artificial intelligence, gene therapy, imaging, neurophysiology, invasive and non-invasive neuromodulation, and hopefully a host of as yet unimagined techniques.
- *Transformations happen at the cross section where two or more fields meet.* We are seeking those who collaborate, who are willing to present their ideas in the service of our end goal, and then adapt and pivot as what is needed in service of the primary goal becomes clearer over time. We are not afraid to take risks and fail. We did not put a man on the moon without making mistakes along the way.

## Big Idea Summits

- The RCP will create yearly gatherings for senior scientists to gather and exchange ideas about how to achieve the mission goals. These gatherings, Big Ideas Summits, will have a general theme but be a free form open idea forum where the top experts across multiple fields can share ideas without the need to follow any agenda or protocol. No idea is too crazy.
- Big Idea Summits are different from other research conferences --- there are NO speeches, no presentations of papers. The summits are a free exchange of ideas between the best scientists from a wide cross section of fields that touch the Cerebellum including cerebellar scientists, imaging experts, data scientists, AI leaders, geneticists, etc all with the goal of creating new ideas in support of the mission to improve the lives of those with Cerebellar disease in as short as time as possible.
- Funding will also be provided for a yearly Post-Doc/Graduate version of the Summits – to allow a place for those younger but exceptional thought leaders to gather and exchange ideas to help push the mission goal forward.
- Candidates for future funding will be identified primarily from attendees at these conferences. Summit attendees will be asked to form collaborations with other attendees across specialties as well as reaching out to different labs with the expertise needed to get the job done.
- Each of these groups will be given a *minimum* of \$4 million to \$5 million each in support of a different facet in support of the RCP's mission --- one team has to build the rocket, one team has to build the lunar module, one team has to build the computers that will map the telemetry. It is contemplated that as many as six consortiums will be chosen to receive such funding over the next several years and they will be expected to work together as a sort of virtual institute in support of the RCP mission.

### The Resources Available -- The \$100 million Plan

- The RCP's parent organization --- The Once Upon a Time Foundation, a \$250 million Foundation based in Fort Worth, Texas --- has allocated **\$30 million** to the RCP for the initiatives outlined in this plan above
- This is in addition to the **\$14 million** that has already been funded to launch the Raynor Cerebellum Lab at UT Southwestern which is in the process of being launched.
- Once Upon a Time provides continual administrative and financial support for RCP initiatives.
- The RCP anticipates raising an **additional \$50 million** through additional commitments from the Once Upon a Time Foundation as well as building outside partnerships with other funding sources.

### The Team:

- On August 4, 2023, the Raynor Cerebellum Project (RCP) announced the appointment of three leading Neuroscientists to the RCP Governing Board:
  - o **Adam Hantman, Ph.D.**
  - o **Stephen G. Lisberger, Ph.D.**
  - o **Roy Sillitoe, Ph.D.**
- The RCP Governing Board is a highly compensated position, with specific time commitments and significant responsibilities. Governing Board Members each spend 20% of their time devoted to the development, growth, and expansion of the RCP's initiatives. Collectively, the three Governing Board members' efforts fulfill the role of the RCP Executive Director. The RCP governing board will work alongside researchers and clinicians at all steps of every project, sharing expertise and skill sets to cross-fertilize existing ideas and improve and troubleshoot to generate unexpected new directions.
- The RCP Advisory Board currently consists of **Peter Tsai, M.D., Ph.D., and Vikram Shakkottai, M.D., Ph.D.**, of UT Southwestern Medical Center. The Advisory Board role is an unpaid, scientific advisory position and we anticipate this board will grow substantially in number in coming months. Members of the Advisory Board are consulted on an as-needed basis.
- **Geoffrey Raynor** is the Founder of the Raynor Cerebellum Project and The Once Upon a Time Foundation. He has a very personal connection to Cerebellar disease. Two of his daughters have cerebellar agenesis. He has both the motivation and the resources to assure success of the mission. Failure is not an option for him, or his daughters.