**2019 SETBP1 Society President Report**

**End of Year**

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**Funds Raised - $155,000**

**2019 Total So Far - $29,840**

**2018 & Prior Total - $60,813**

*MDBR - $67,943  **$3,632 is from SS to MDBR*

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### 2019 Highlights

**January**
- Virtual Family Conference - Connected Families, Promoted Research, Spread Awareness, Provided Educational Resources and Motivated Families

**February**
- Worked with consultant with TapRoot to develop resources (information sheet design, newsletter design, t-shirt designs, coffee cup design, etc.)

**March**
- Jackson Labs kicked off SETBP1 KO Conditional Mouse Model Project
- Finalized SETBP1 Society Information Sheet

**April**
- First round of pups produced from JL SETBP1 KO Mouse Project - on track
- SETBP1 Information Sheet translated into SP, DE, NL, FR and IT

**May**
- 13 families have reached out to Dr Angela Morgan at MCRI for her speech study
- Million Dollar Bike Ride & SETBP1 Family Meetup - raised $67,934
- 2 SETBP1 Board Members Attended Rare Drug Symposium in Philly

**June**
- Launched website in multiple languages
- Mailed Education & Awareness Campaign to 1000 Medical Specialists
- Attended 3rd Global Genes Summit
- 1st SETBP1 Collaboration Call

**July**
- Dr Simon Fisher received IRB approval for grant
- Attended NORD Conference - 1st time
- Reviewed 5 SETBP1 grants for MDBR grant
- 20 families fully enrolled in Dr Angela Morgan's Speech & Language Study

**August**
- Launched SETBP1 Society Registry

**September**
- Giving Tuesday brought in $17,025 so far (Facebook matching not included)!!
- Launched SETBP1 disorder Awareness Video
- Dr Carl Ernst from McGill selected as the MDBR SETBP1 disorder grant awardee
- Wrapping up enrollment for Dr Angela Morgan's Speech & Language (MCRI) Study

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**62 Families**
- SETBP1

**22 Families**
- SIMONS SEARCHLIGHT

**13 Families**
- SETBP1 REGISTRY
2020 Looking Ahead

**January**
- Finalize Mouse Model Research Grant Goals & Application Details
- Rare Disease Day - Opportunity to Spread Awareness and Launch 2nd Video
- Open up Mouse Model Grant Applications for Proposals
- SETBP1 KO and deletion mice should be available to researchers by JAX
- Quarterly SETBP1 Collaboration Call (2nd)

**February**
- Review SETBP1 mouse model grants
- Announce SETBP1 mouse model grant recipient, Promote Conference Registration

**March/April**
- MDBR hosted by UPenn ODC in Philly
- SETBP1 Family & Research Conference in Baltimore, MD
- Dr Angela Morgan’s Final Research Shared at Conference & Dr Sid’s Research

**April/May**
- Global Genes Summit OR NORD Conference
- Review MBR grants
- Quarterly SETBP1 Collaboration Call

**June**
- GivingTuesday Fundraiser
- MDBR SETBP1 grant recipient announced

**August**
- SETBP1 Family & Research Conference in Baltimore, MD
- Dr Angela Morgan’s Final Research Shared at Conference & Dr Sid’s Research

**September/October/November/December**
- Global Genes Summit OR NORD Conference
- Review MDBR grants
- Quarterly SETBP1 Collaboration Call

2020 Primary Focuses

Educate, Build Community & Drive Engagement with the Family & Research Conference
Commit to at least 2 Fundraisers (Million Dollar Bike Ride & Giving Tuesday)
Help Initiate More SETBP1 Research, Monitor Currently Funded Grants/Projects, and Recruit for Research
Organize SETBP1 collaboration calls with researchers, MSAB, Board, and specialists
Consider Ideas for Diagnostic Journey research

Expenses - $18,969.58
Income - $29,840

*Marketing Expenses covered by Ovid Grant*