

# 2019 SETBP1 Society President Report

## End of Year



*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



## 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
- May** - SETBP1 Information Sheet translated into SP, DE, NL, FR and IT
- June** - 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
- July** - 2 SETBP1 Board Members Attended Rare Drug Symposium in Philly
- August** - Launched our website in multiple languages
- September** - Mailed Education & Awareness Campaign to 1000 Medical Specialists
- October** - Attended 3rd Global Genes Summit  
- 1st SETBP1 Collaboration Call
- November** - 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
- December** - Launched SETBP1 Society Registry  
- Giving Tuesday brought in \$17,025 so far (Facebook matching not included)!!  
- Launched SETBP1 disorder Awareness Video  
- Dr Carl Ernst from MGill selected as the MDBR SETBP1 disorder grant awardee  
- Wrapping up enrollment for Dr Angela Morgan's Speech & Language (MCRI) Study

**62**  
*Families*



**22**  
*Families*



**13**  
*Families*



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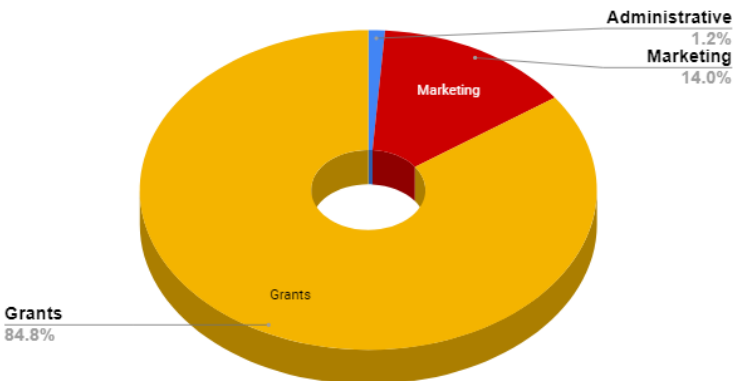
### 2020 Looking Ahead

- January** - Finalize Mouse Model Research Grant Goals & Application Details
- February** - 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)
- March/April** - Review SETBP1 mouse model grants
- April/May** - Announce SETBP1 mouse model grant recipient, Promote Conference Registration
  - Quarterly SETBP1 Collaboration Call
- June** - MDBR hosted by UPenn ODC in Philly
- August** - SETBP1 Family & Research Conference in Baltimore, MD
  - Dr Angela Morgan's Final Research Shared at Conference & Dr Sid's Research
- September** - Global Genes Summit OR NORD Conference
- /October** - Review MDBR grants
- /November** - Quarterly SETBP1 Collaboration Call
- December** - GivingTuesday Fundraiser
  - MDBR SETBP1 grant recipient announced

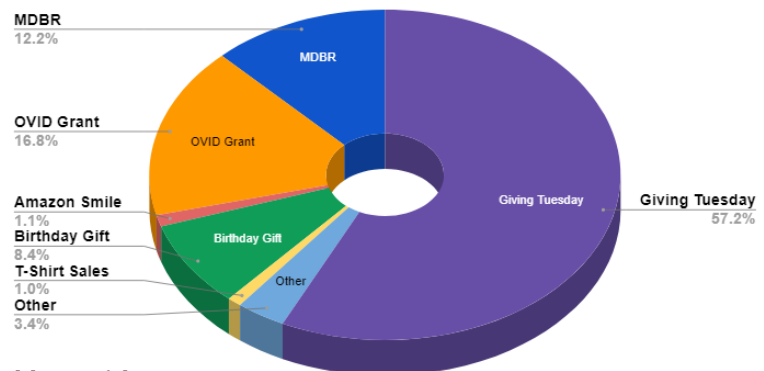
### 2020 Primary Focuses

- 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