

# 2020 SETBP1 Society End of Year Report



**Total SETBP1 Funds Raised - \$283,585\***  
*SETBP1 Society Funds Raised - \$143,367*  
**2020 SETBP1 Society \$52,302 & Total \$128,209**

\*MDBR - 2020 \$80,746 / 2019 \$67,943, committed by EOY 2020



## COMMUNITY

- Simons Searchlight hosted our 3rd Annual Virtual SETBP1 disorder Community Virtual Conference in partnership with SETBP1 Society
- Hosted numerous Family Chats throughout the year for families to connect virtually
- Completed and shared the 2020 Community Survey to better understand community's needs
- Added our newest Board members, Lindsey Noonan & Nicole Wentz

## RESEARCH

- Dr Bregje van Bon's SETBP1 disorder phenotype paper is out for peer review
- Dr Angela Morgan's SETBP1 disorder speech/language phenotype paper is out for peer review
- Our partnership with Jackson Labs culminated with the development of 2 SETBP1 disorder mice and the initial characterization and study of the mice at Baylor/TCH
- Participated with 30+ rare disease groups in the Million Dollar Bike Ride and raised \$80,746 to fund 2 new SETBP1 disorder research projects
- Hosted 2 SETBP1 Collaboration Calls to unite our SETBP1 research and medical community
- Simons Searchlight hosted 1st SETBP1 Research & Medical Conference in partnership with SETBP1 Society
- Simons Searchlight iPSc line development initiated for 4 SETBP1 samples bio-banked through our registry - expected availability Q2 2021
- 4 new SETBP1 research projects kicked off this year at Baylor, UNC, UAH & TSU
- Applied for Healx Grant - good collaborative effort with the SGS Foundation

## AWARENESS

- 2 volunteers joined our team to expand public relations and social media presence
- Successfully launched our first 2 press releases
- Attended the virtual annual NORD and Global Genes conferences
- President, Haley Oyler, interview about SETBP1 Society with COMBINEDBrain
- 2 Board members attended and cultivated relationships the Global Genes Data DIY event in Houston

# 2020 SETBP1 Society President Report

## End of Year



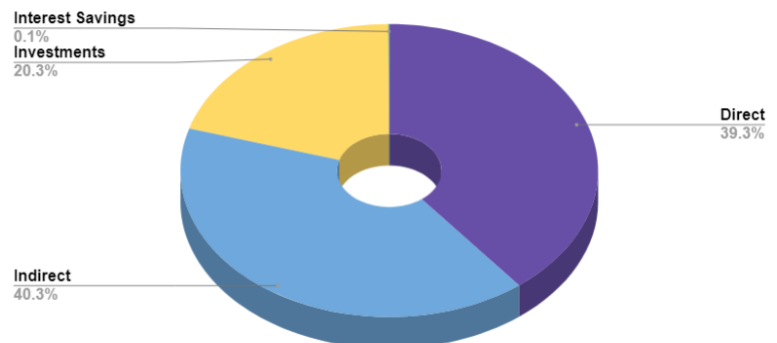
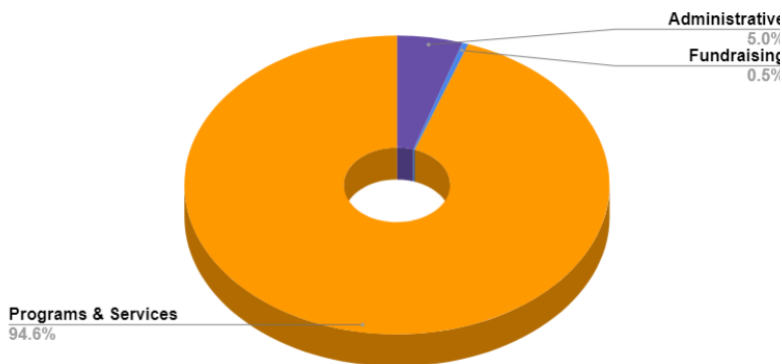
### 2020 Primary Focuses

- 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

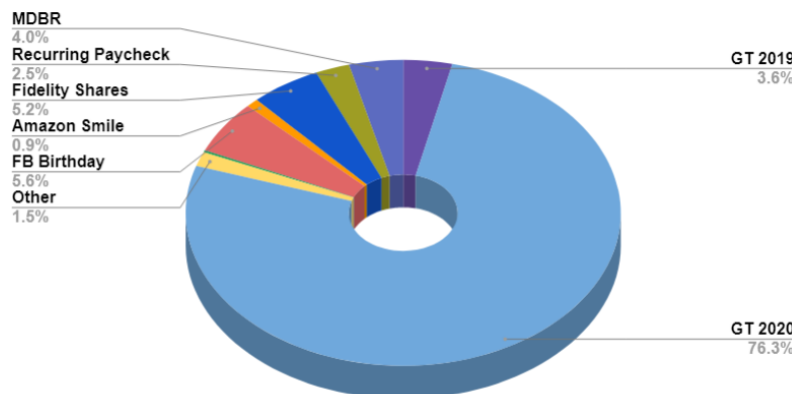


Expenses - \$12,164

Income Received - \$29,837



### Donations Committed by Program





## 2021 Looking Ahead

- 1st Qtr**
  - Develop research grant proposals with targeted researchers
  - Rare Disease Day - Opportunity to Spread Awareness
  - Family Chats (9+ throughout the year)
  - Quarterly SETBP1 Collaboration Call
  - Dr Morgan/Haley Oyler Apraxia webinar
  - Dr Morgan and Dr van Bon's publications (tentative dates to be published)
- 2nd Qtr**
  - Launch Parent Study through Collaboration project with Tarleton State University
  - Simons Foundation SETBP1 iPSCs made available to researchers
  - Finalize SETBP1 Alliance CRN plans
  - Quarterly SETBP1 Collaboration Call
- 3rd Qtr**
  - MDBR hosted by UPenn ODC in Philly
  - Kick-off SETBP1 Biomarker & Surrogate Endpoint study with Baylor/TCH
  - SETBP1 Family & Research Conference (virtual)
- 4th Qtr**
  - Global Genes Summit and/or R NORD Conference
  - Develop, Distribute and Share results from 2021 Community Survey
  - Review MDBR grants
  - Quarterly SETBP1 Collaboration Call
  - GivingTuesday Fundraiser
  - MDBR SETBP1 grant recipient(s) announced

## 2021 Primary Focuses

- Educate, Unite Community & Drive Engagement with the Family & Research Conference, Family Chats, Social Media Presence, Education Events, and in-person Events (when possible)
- Commit to at least 2 Fundraisers (Million Dollar Bike Ride & GivingTuesday)
- Build the SETBP1 research network through organization of SETBP1 Alliance Collaborative Research Network, SETBP1 Collaboration Calls, Funding & Promoting Research, Partnering with the SGS Foundation and Cultivating Relationships
- Continue to promote and fund research focused on expanding research tools for studying SETBP1 disorder, identifying affected pathways or targets for treatment, and validation of identified molecular targets (biomarkers & surrogate endpoints)

We are fighting everyday to give our kids their best life. SETBP1 Society is there with you providing resources and encouragement. We are supporting & funding research to identify more ways to help our kids. Thank you community for your love & support!

Be the Hope! Be the Change!

Sincerely, Haley Oyler - President & Founder