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

99 Families
SETBP1

44/23 Families
SIMONS SEARCHLIGHT

36 Families
SETBP1 REGISTRY

Expenses - $12,164
Income Received - $29,837

Income Committed by Program - $52,302.68
### 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
- Quarterly SETBP1 Collaboration Call
- MDBR hosted by UPenn ODC in Philly

#### 3rd Qtr
- Kick-off SETBP1 Biomarker & Surrogate Endpoint study with Baylor/TCH
- SETBP1 Family & Research Conference (virtual)
- Global Genes Summit and/or R NORD Conference

#### 4th Qtr
- 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 SETBP1Alliance 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