

2017 SETBP1 Society Annual Report

BY THE NUMBERS



Non-profit Organization

5 BOARD MEMBERS

4 PROFESSIONALS ON MEDICAL ADVISORY BOARD

20+ SETBP1 FAMILIES

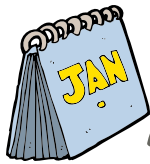
Support Community

Community grew from 3 to 23

7 Countries Represented



Newsletters Released



Upcoming Virtual Family Conference



13th

October



SETBP1 disorder added to

GARD Genetic and Rare Diseases Information Center



Brochure Crafted



Rare Disorder Conference
Global Genes
Patient Advocacy Summit

Promote Research

>\$12K Funds Raised



150 Unique Donors

11 families enrolled



Partners Researchers

5

43

22

8

Patient Groups Biotech organization connections established



of SETBP1 Faces on SETBP1 website

Spread Awareness

SETBP1 Society
Established

1st



Website Launched



SETBP1 Story Published
Unique Magazine - Winter 2017