



FEBRUARY 28TH IS RARE DISEASE DAY. CURRENTLY, THERE ARE OVER 7,000 KNOWN RARE DISEASES. HISTORICALLY, THERE HAS BEEN MINIMAL FUNDING DIRECTED TO RESEARCH FOR RARE DISEASES.

MELISSA ROBILLARD, A VOLUNTEER AT SCIL FOR MORE THAN SIXTEEN YEARS, WAS BORN WITH A RARE GENETIC DISEASE CALLED LEUKODYSTROPHY, SPECIFICALLY VANISHING WHITE MATTER DISEASE (VWM). THIS PROGRESSIVE NEUROLOGICAL DISEASE EFFECTS THE WHITE MATTER OF THE BRAIN.

IN SPITE OF THE DECLINE, MELISSA HAS EXPERIENCED OVER TIME SHE ACTIVELY ENGAGES IN HER LIFE. A GREAT ACHIEVEMENT OCCURRED IN MAY 2016.

MELISSA PUBLISHED HER CHILDREN'S BOOK, "SNOWBALL'S GREAT ADVENTURE."

SHE AND HER FAMILY HAVE CHOSEN TO DEVOTE TO RAISING AWARENESS ABOUT VWM. THEY ARE ALSO DONATING A PERCENTAGE OF PROCEEDS FROM THE SALE OF THE BOOK TO RESEARCH.

MELISSA, HER FAMILY, AND HER PCA, JANINE OUELLETTE SULLIVAN ARE PLANNING FUNDRAISERS FOR 2017. THE MONEY THEY RAISE WILL GO DIRECTLY TO RESEARCH. MELISSA BELIEVES THAT IT IS IMPORTANT TO RAISE AWARENESS ABOUT LEUKODYSTROPHY AS WELL AS FUNDS FOR RESEARCH.

**Find A Cure for VWM- Research
Make donations to:**

**AFTAU Mail to: American Friends of Tel Aviv University
39 Broadway, Suite 1510 New York, NY 10006
Attention: Joe Heiber/Orna VWM Research**

OR

**www.aftau.org/vwm or
www.crowdrise.com/FindACureforVWM**

To learn more please visit:

www.snowballsgreatadventure.wordpress.com

