

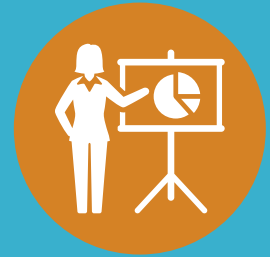
AWARENESS



14,000 website visits



458 donors



4 international presentations

RESEARCH



6 ongoing projects



Care Management Guidelines



Supported creation of new organization



Patient Registry 145 enrollees

SUPPORT



Welcomed 14 new families



181 registrants, 29 countries
7 languages



Conference boxes to 149 families



Private support group 298 members

OPERATIONS



Expenses \$55,000



Income \$88,000