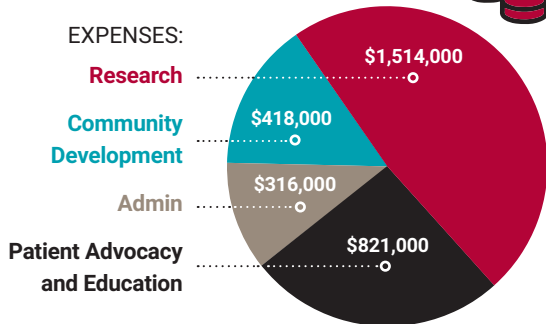


OVERCOMING OBSTACLES BECAUSE **TIME = LIVES**

Regardless of what is happening in the world, facioscapulohumeral muscular dystrophy (FSHD) does not stop its devastating progression, and neither can we. Your involvement, your support, and your commitment to the FSHD Society, and our collective mission, ensures that no one need ever face this disease alone.

FINANCIALS (modified cash basis)

REVENUE RAISED: **\$3,173,000**



PERSONAL STRENGTHS

SEQUESTER CAMP/FSHD UNIVERSITY: Empowering individuals to be their best self; average reach 1,500 people



FSHD FAMILY DAYS: Focusing on connecting community, clinicians, and researchers; intensive, in-person



CHAPTER & OTHER MEETINGS/ PROGRAMS: 62 chapter meetings, 29 educational programs, 27 fundraising events

DEEPENING COMMUNITY

CONNECT CONFERENCE: 2018 vs. 2020 – 237 attendees vs. 404 attendees

NUMBER OF CHAPTERS: 28 chapters

VIRTUAL WALK & ROLL: 3,600 participants/supporters \$554,000 raised

NEWLY IDENTIFIED MEMBERS: 3,848 members – 25% increase

NEWLY ENGAGED MEMBERS: 2,113 members – 39% increase



ADVANCING RESEARCH



CLINICAL TRIAL RESEARCH NETWORK: 18 sites worldwide; FSHD Society investment of \$900,000 over 3 years; 7 new sites launched in 2020 through pharmaceutical and FSHD Society partnerships

INTERNATIONAL RESEARCH CONGRESS: 280 participants, 50% increase (virtual)

BIOMARKER PROJECT LAUNCH: pilot studies that look promising

THERAPIES IN DEVELOPMENT: 12

VOICE OF THE PATIENT FORUM: landmark report for the FDA on the impact of FSHD

TREATMENTS FOR FSHD

