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)

<table>
<thead>
<tr>
<th>Revenue Raised</th>
<th>$3,173,000</th>
</tr>
</thead>
<tbody>
<tr>
<td>Expenses:</td>
<td></td>
</tr>
<tr>
<td>Research</td>
<td>$1,514,000</td>
</tr>
<tr>
<td>Community</td>
<td>$418,000</td>
</tr>
<tr>
<td>Development</td>
<td>$316,000</td>
</tr>
<tr>
<td>Admin</td>
<td>$821,000</td>
</tr>
<tr>
<td>Patient Advocacy and Education</td>
<td>$418,000</td>
</tr>
</tbody>
</table>

**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

**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

**TREATMENTS FOR FSHD**

- **JUNE 2019** International Research Congress (Europe)/25 chapters
- **OCTOBER 2018** 15 chapters & National Walk & Roll/planning for Industry FDA Meeting
- **MARCH 2019** FDA/Industry Collaborative Meeting/19 chapters
- **JUNE 2018** Therapeutic Accelerator and chapter initiatives launched
- **OCTOBER 2019** Workshops planned/27 chapters/18 volunteer events raised $800k!
- **2020** Launched targeted research initiatives/FDA Voice of the Patient Forum and Report/28 chapters and 27 fundraising events
- **2020–2021** Drive projects eliminating existing gaps currently hindering trials and drug approval for FSHD/expand & deepen community engagement
- **2022–2023** Finish projects & evaluate impact/5+ trials/first potential therapy submitted to FDA

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