

Parent Project Muscular Dystrophy



...fights to end Duchenne.

We accelerate research, raise our voices to impact policy, demand optimal care for every single family, and strive to ensure access to approved therapies.

RESEARCH



\$50 million+

invested by PPMD
into Duchenne
research & therapy
development to date



**Over 260
research grants**

awarded, supporting
nearly every major
therapeutic approach



~ 35 clinical trials

in Duchenne
at any given time



2 US drug approvals

with additional
promising therapies
in development

ADVOCACY



4 bills

signed into law,
reshaping the
Duchenne landscape



**12000 messages &
action alerts**

sent to Members
of Congress



Over \$600 million

in federal funding
leveraged by
PPMD community
into research



**More than 2000
meetings**

face-to-face with
Members of Congress

CARE



10 years

added to average
lifespan due to
PPMD-led advances
in care



25 clinics

awarded certification
by PPMD across the US
as of June 2019



700 care providers

in PPMD network
of certified clinics



20 years

of identifying &
addressing gaps
in care through
specialty workshops
& consensus meetings

ENGAGEMENT



**26 PPMD Connect
locations**

across the United States,
providing local families
outreach & mentoring



**Over 5000 patients
& carriers**

across the globe
have registered in
The Duchenne Registry
since launch



\$36 million+

raised through
Race to End Duchenne
& family-led grassroots
events since 1994



14310 families

reached in person, through
25 Annual Conferences,
End Duchenne Tour stops,
Roundtable discussions,
& Advocacy Conferences

- **We demand optimal care standards** and ensure every family has access to expert healthcare providers, cutting edge treatments, and a community of support.
- **We invest deeply** in treatments for this generation of Duchenne patients and **in research** that will benefit future generations.
- Our **advocacy** efforts have **secured hundreds of millions of dollars** in funding and won **two FDA approvals**.
- **Everything we do**—and everything we have done since our founding in 1994—**helps those with Duchenne live longer, stronger lives**. We will not rest until we end Duchenne for every single person affected by the disease.