

2018 MDCC Member Organization Support for Muscular Dystrophy Research

Emily Carifi
Emily.Carifi@nih.gov

Health Program Specialist,
Neurogenetics Cluster
National Institute of Neurological Disorders and Stroke
(NINDS)

Reporting MDCC Organizations

Federal

- Centers of Disease Control and Prevention
- Department of Defense, CDMRP (DMDRP, PMRP#)
- NIH (NCATS, NEI, NHLBI, NIA, NIAMS, NICHD, NIDCR, NIGMS, NINDS, NINR, NLM, OD)

Private

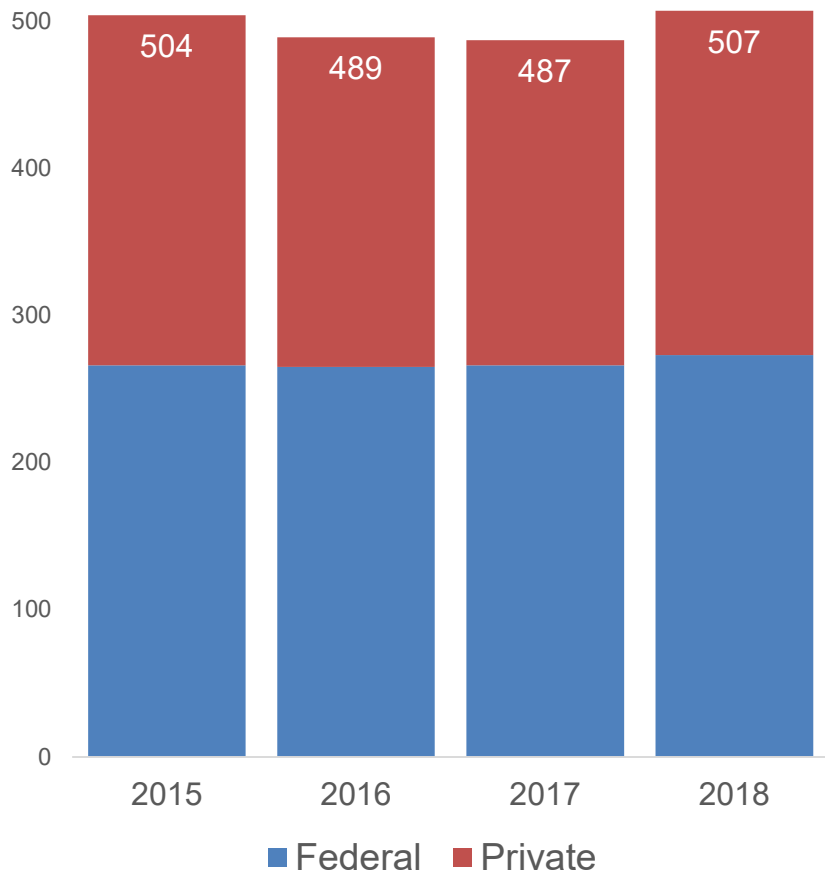
- Coalition to Cure Calpain 3*
- CureCMD*
- FSH Society
- Jain Foundation
- Muscular Dystrophy Association
- Myotonic Dystrophy Foundation/Wyck Foundation
- Parent Project Muscular Dystrophy

Grant Coding relevant to action plan

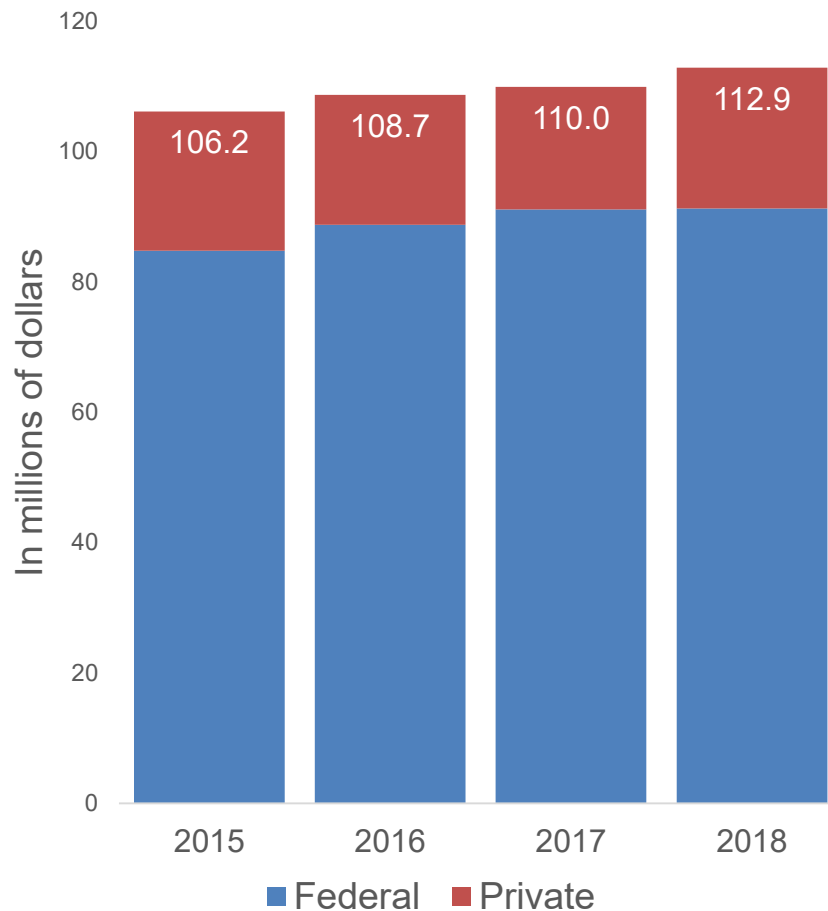
- **Purpose of grant***
 - Research activities
 - Research infrastructure
 - Training (workforce development)
 - Conference support
 - Patient services
- **Type of dystrophy***
 - Duchenne/Becker
 - Myotonic
 - Facioscapulohumeral
 - Congenital
 - Limb-girdle
 - Pan/multiple dystrophies (added in 2016)
 - Other
- **Action Plan relevant categories (by %)**
 - Understanding causes
 - Screening and diagnosis
 - Developing or improving therapies
 - Clinical trial readiness (biomarkers, outcome measures, cohort characterization, etc)
 - Patient care, disease management, access to services (including research on QoL, disease burden, economic impact, etc)
 - Other (administrative activities, etc)

Support for Muscular Dystrophy Research by MDCC Member Organizations 2015-2018

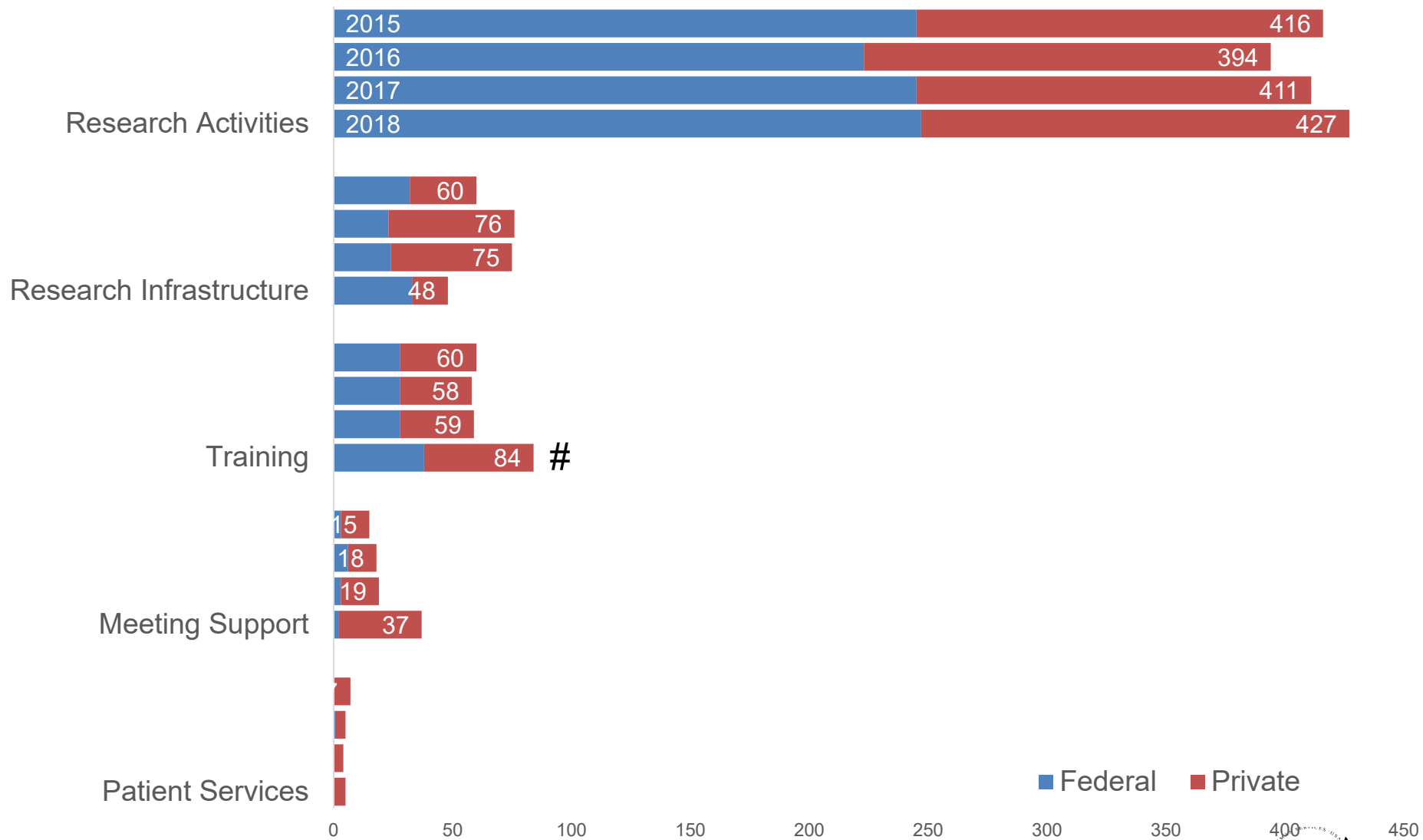
Number of Grants



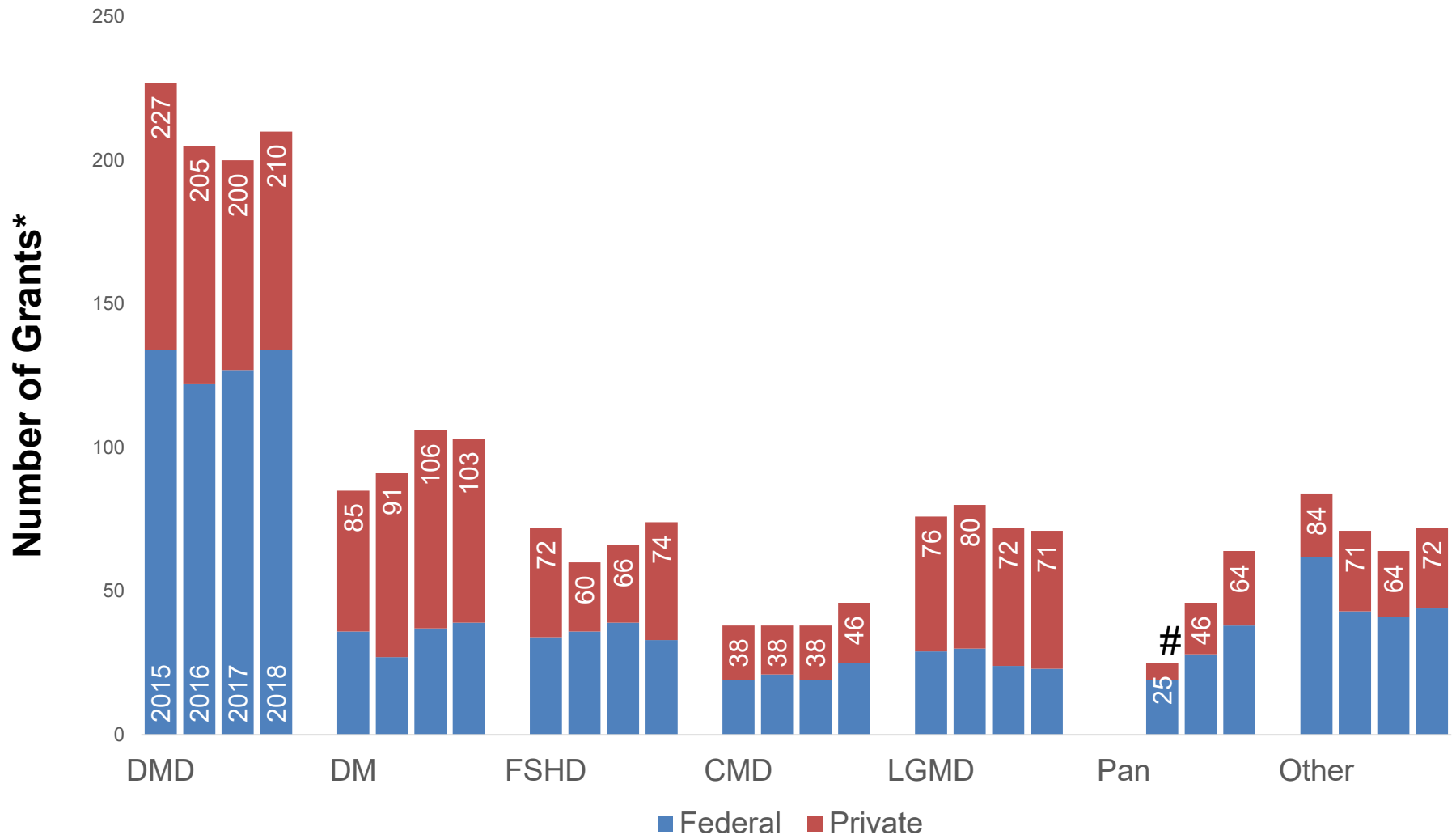
Estimated* Award Total in Millions of dollars



2015-2018 Support by Grant Purpose



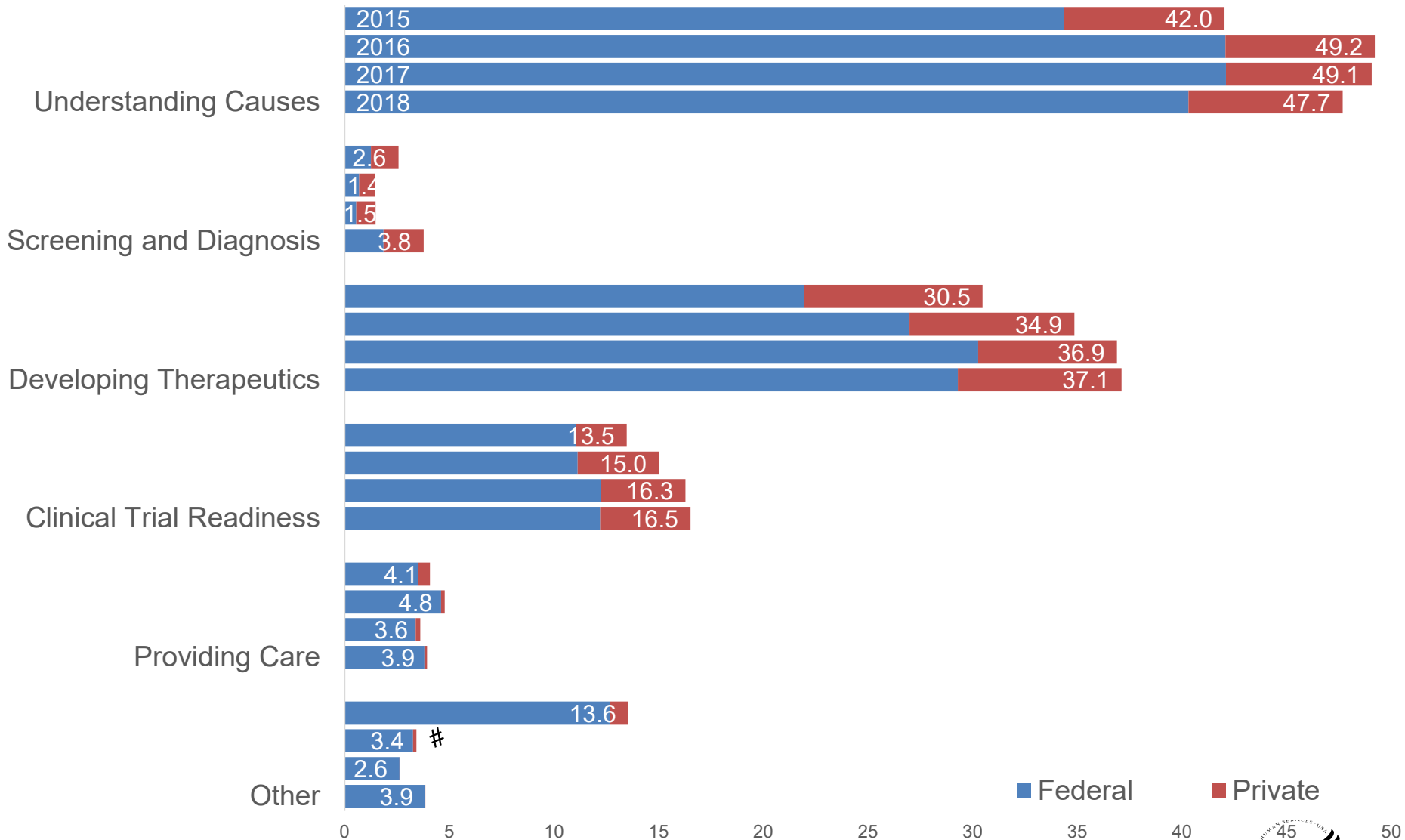
2015-2018 Number of Grants by Disease



pan category added 2016

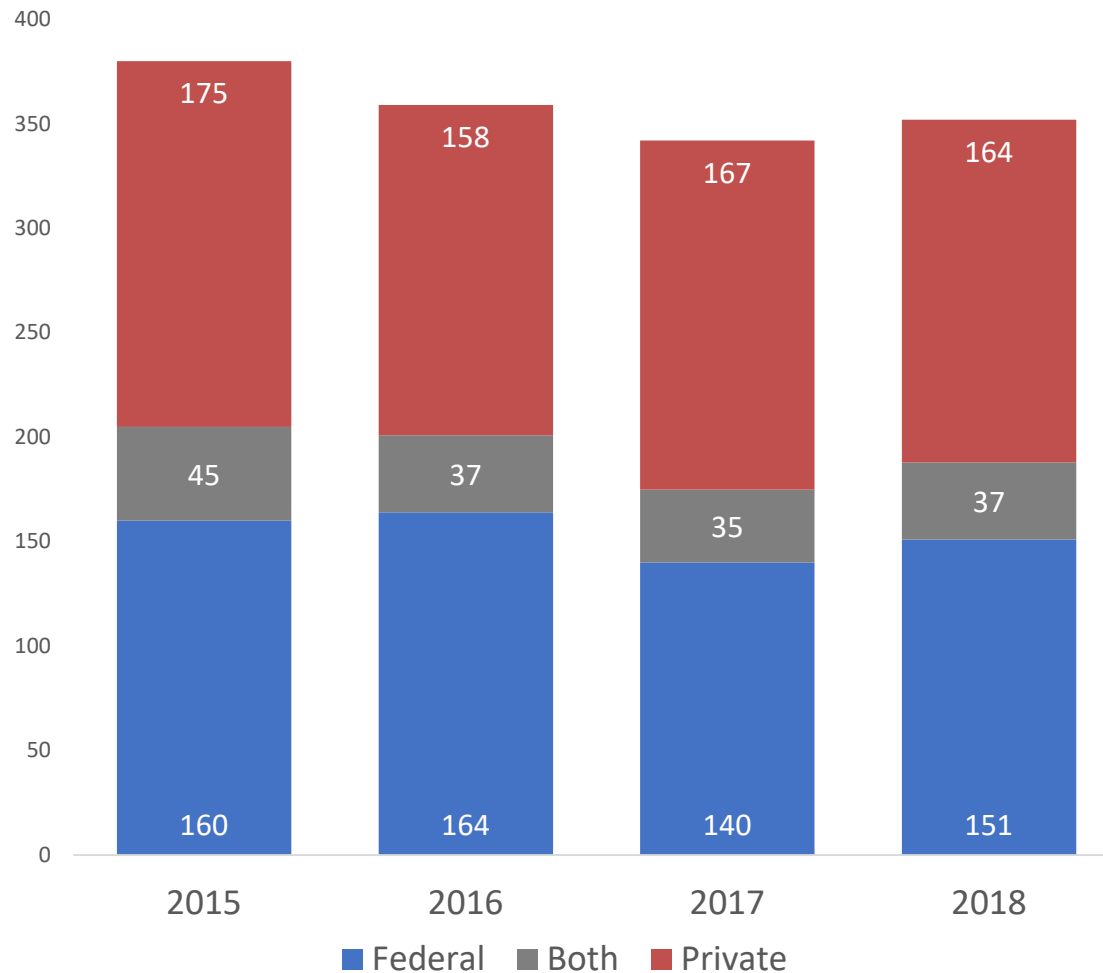
*grants can apply to more than one disease

2015-2018 Estimated* \$ Amount for Each Category (in millions of dollars)



Sources of Funding for Independent Muscular Dystrophy Researchers 2015-2018

Number of individual PIs



The next generation of muscular dystrophy researchers

Independent Trainee awardees

36 in 2015

46 in 2016

57 in 2017

64 in 2018

New Investigator awardees (NIH independent investigator only)

1 in 2015

7 in 2016

5 in 2017

2 in 2018

**7 independent trainees
from 2015**

**Have a 2018 independent
research grant from NIH**

**2 from patient groups
5 from NIH**

Summary

- **Modest support increases year by year**
- **Numbers of independent trainee awards remains high – both private and federal funding**
- **Most of the support for research is aimed at understanding causes and developing therapies**
- **Annual collection and analysis of these data provide a “high altitude” view of the status of the workforce, progress of the research, and eventually investigator investment.**
- **How are these data being used by the community – any suggestions for future analysis?**