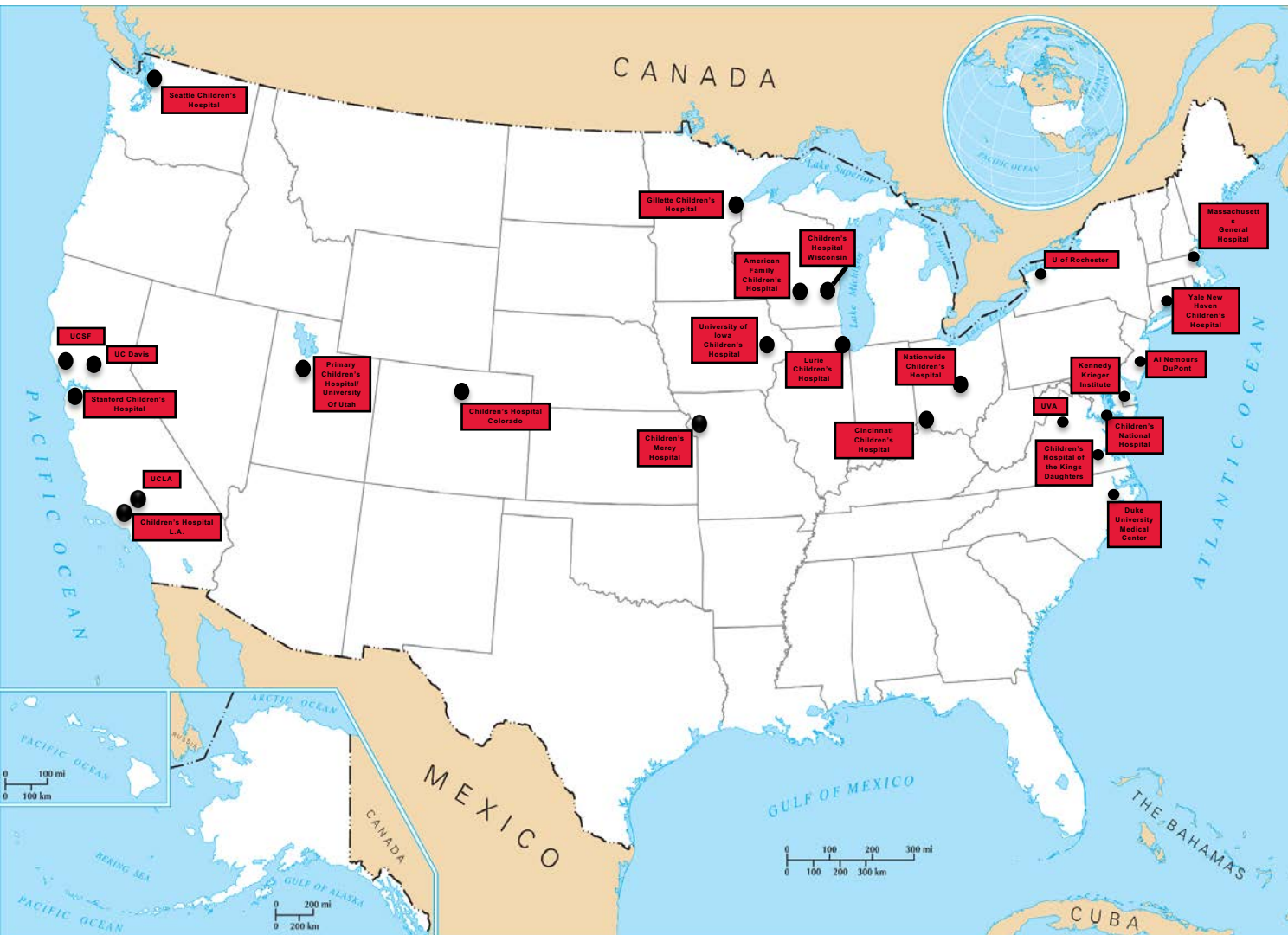


Improvements in Care: Extending the Quality of Life with a Focus on the Future

**Parent
Project
Muscular
Dystrophy**

JOIN THE FIGHT.
END DUCHENNE.

Kathi Kinnett, MSN, APRN
SVP Clinical Care
PPMD Conference 2019



2019 PPMD's 25 US CDCCs, 1 Global CDCC



CDCC Program Accomplishments

- 25 US CDCCs
 - 1 Global CDCC
- New Adult CDCCs
- Expanded Global Certification Effort



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CDCC Accomplishments

- >700 Healthcare Providers
- 80% of CDCCs are major clinical trial sites
- Those that are not are major referral sources to other clinical trial sites



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Maintaining the Highest Standards

- Annual center updates
 - Changes in staff and faculty
 - Changes in clinical practice
- Biannual community reports
 - Just published



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Why we Need Your Help!

- Clinical Experiences Surveys
 - Your **annual** perception of the care and services at your CDCC
 - Continuous quality improvement
 - Biannual report just published



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Impact and Progress - Just Published

EVALUATING YOUR CARE AND SERVICES

Between January 2018 and January 2019, 363 Clinical Experiences Surveys were completed across 23 Certified Duchenne Care Centers. Patient ages across the CDCCs ranged from 1 – 60 years old, with the greatest percentage being between 5 – 18 years old (80.21%). In the past 18 months, parents and patients report:

- 241 are taking corticosteroids (prednisone: 86; deflazacort 139).
- 180 are taking daily steroids and 51 are taking weekend doses.
- 80.2% received the influenza vaccine.
- 245/342 received a copy of their last note or have access to the note in EHR
- 94% received a pulmonary function test
- 92% had cardiac imaging (echocardiogram 41%, cMRI 14%)
- 90% have had genetic testing
- 69% reported having their vitamin D levels checked (25 OH vitamin D)
- Nearly all patients reported having seen a neuromuscular specialist, cardiology, pulmonary, physical therapy. More than 50% had seen social work, nutrition and occupational therapy
- Clinical trials discussions were reported by 60% of patients/parents
- 75% of patients were encouraged to update their information in [The Duchenne Registry](#)
- 25% of patients reported being involved currently in a clinical trial or an extension phase of a clinical trial
- 97% of participants reported being satisfied (24%) or very satisfied (73%) with their care



Clinical Experiences Surveys

- 363 collected January 2018 – January 2019
- 241 are taking steroids (86 prednisone, 139 Deflazacort)
- 180 are taking daily steroids; 51 weekend dosing
- Care
 - 94% PFT
 - 92% Cardiac Imaging



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Clinical Experiences Surveys

- Clinical trials: discussed with 69%
- 75% were encouraged to update their information in The Duchenne Registry
- 97% are satisfied/very satisfied with their care
 - 73% are very satisfied
 - 24% are satisfied



Addressing Gaps in Care

- 2018: Contractures in Duchenne and Other Neuromuscular Conditions
 - Most updated information related to stretching, bracing, contracture risk, prevention and maintenance
 - Updated PT videos
 - New PT handout for parents, patients and PT's



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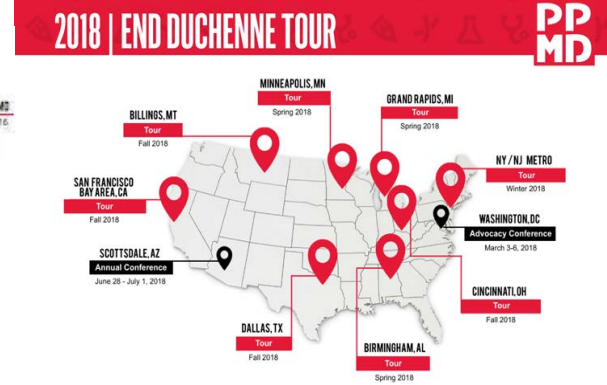
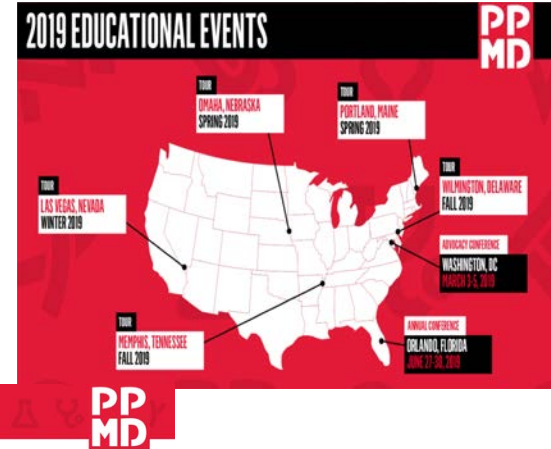
Addressing Gaps in Resources

End Duchenne Tours

- Only over the past 4 years: 26 in person, 1 virtual tour:

Spanish Resources

- Imperatives for DUCHENNE MD, Emergency Cards, Wheelchair Emergency Cards, PJ Nicholoff Steroid Protocol
- Spanish EDT recorded Webinar



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Addressing Gaps in Resources

- Online Resources
 - Updated Family Guide
 - Emergency information
 - Emergency information, emergency numbers
 - New Diagnosis Information – coming!!!
 - Updated subspecialty information
 - Rehabilitation, pulmonary, bone health
 - Education Matters
 - MMR: Updated Vaccination Information



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Connecting CDCCs to Optimize Care

- Healthcare Professionals Summit
 - 2018: Updates in Care
 - 2019: Building collaborations across the network
 - 2020: Agenda is in process; continued collaborations



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Platform Trial

Newborn Screening

The Duchenne Registry

ICD 10
Code

CARE

Access to
Therapies

CDC

Industry Partnerships
Clinical Trials

FDA

Continuing Progress

- Care for newborns
- Decode Duchenne
 - Now patient and carrier testing
- The Duchenne Registry
 - PRO + EHR
 - ICD 10 Code and EHR
- Platform Trials
- Adult Duchenne Care



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Thank you!