

American Academy
for Cerebral Palsy and
Developmental Medicine



Dear Pedal with Pete Foundation:

Thank you for your continued support the American Academy for Cerebral Palsy and Developmental Medicine. Your grant sponsorship helps achieve one of the Academy's key missions-promoting excellence in research for the benefit of persons with cerebral palsy and childhood-onset disabilities.

Over a **nine-year** span, Pedal-with-Pete has supported a total of **20** research grants through the Academy.

The outcomes presented in this report are the result of your commitment and continued support of our shared goal for funding high quality research that aims to improve the quality of life for persons with cerebral palsy. We hope you feel the same level of accomplishment in these results as us.

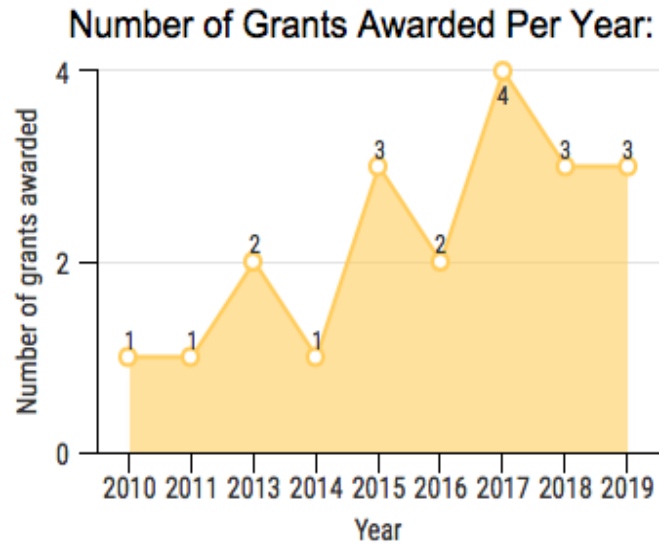
With sincere gratitude,

The American Academy for Cerebral Palsy and Developmental Medicine

Research Committee

Funded Research Projects:

- Collaborative Study of Robotic Assisted Therapy in Children ('10)
- Large Amplitude Training for Children with Cerebral Palsy: A Planning and Feasibility Study ('11)
- Pilot Multi-Center Evaluations of Reflex and Nonreflex Changes in Cerebral Palsy Using a Portable Device ('13)
- Osteoporosis in Children with Cerebral Palsy ('13)
- Outcomes of Hip Intervention for Children with Cerebral Palsy- An International Multi-Centre Prospective Comparative Cohort Study ('14)
- The Effect of Intravenous e-Aminocaproic Acid on Blood Loss and Transfusion Requirements after Bilateral Varus Rotational Osteotomy (VRO): A Prospective, Double-blinded, Randomized Controlled Trial ('15)
- CP2: Community Partners for Children's Participation – Pilot Project and Feasibility Study ('15)
- Development of ICF-based Multimedia Education Modules and their Impact on Mothers' Knowledge and Attitude Towards their Children with Cerebral Palsy ('15)
- Linking Neuroplasticity with the Outcomes of Walking-based Interventions: A Feasibility Trial Comparing a Motor Learning Versus A Strength-Based Program in Children with Cerebral Palsy ('16)
- Accessible Methodology to Quantitate General Movements Assessments in Infants at High Risk for Cerebral Palsy ('16)
- Hypoxemia and White Matter Development in the Motor Outcomes of Extremely Preterm Infants ('17)
- Neuroplastic Adaptations of Swallowing and Speech in Cerebral Palsy: A 2-Center Study to Identify New Treatment Targets ('17)
- Multi-Morbidity Risk Assessment and Prevention through Health-Promoting Behaviours (Physical Activity, Nutrition and Sleep) in Adolescents and Adults with Cerebral Palsy ('17)
- Biomarkers for Cerebral Palsy ('17)
- Supported Mobility Across the Lifespan in Cerebral Palsy: Joint Decision Making ('18)
- Participation, Mobility, and Gait in Adults with Cerebral Palsy: Relationships with Childhood Factors ('18)
- Muscle Stem Cell Dysfunction in Muscular Contractures in Children with Cerebral Palsy ('18)
- Use of Collagenase Clostridium Histolyticum to Decrease Muscle Fibre Bundle Stiffness in Cerebral Palsy: A Proof-of-Concept Pilot Study ('19)
- MicroRNAs in Magnesium-Mediated Neuroprotection ('19)
- Reversal of Aged Muscle Stem Cell Dysfunction in Contractured Muscle from Cerebral Palsy ('19)



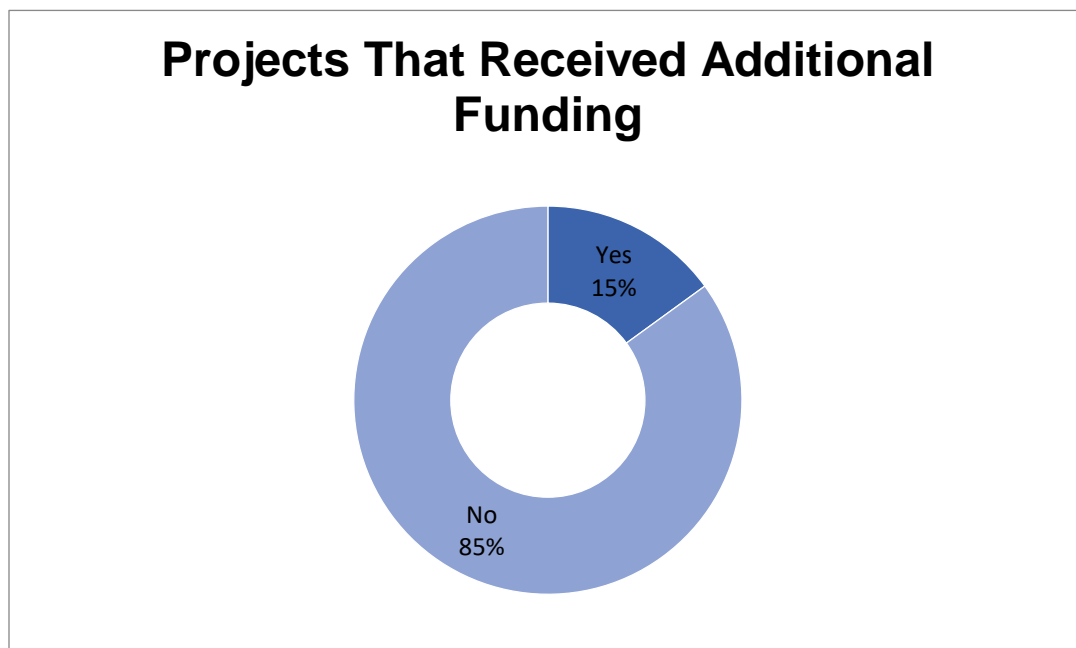
20 Total Research Projects Funded Through AACPD

Total Funding Awarded: \$500,000

Mid-Point Survey Results:

The following data is based on survey results from our Mid-Point Survey, taken by the Project Lead for research grants awarded during the time period of December 2017-December 2019. A total of seven research grants are reported in these results.

Grant that received additional funding:

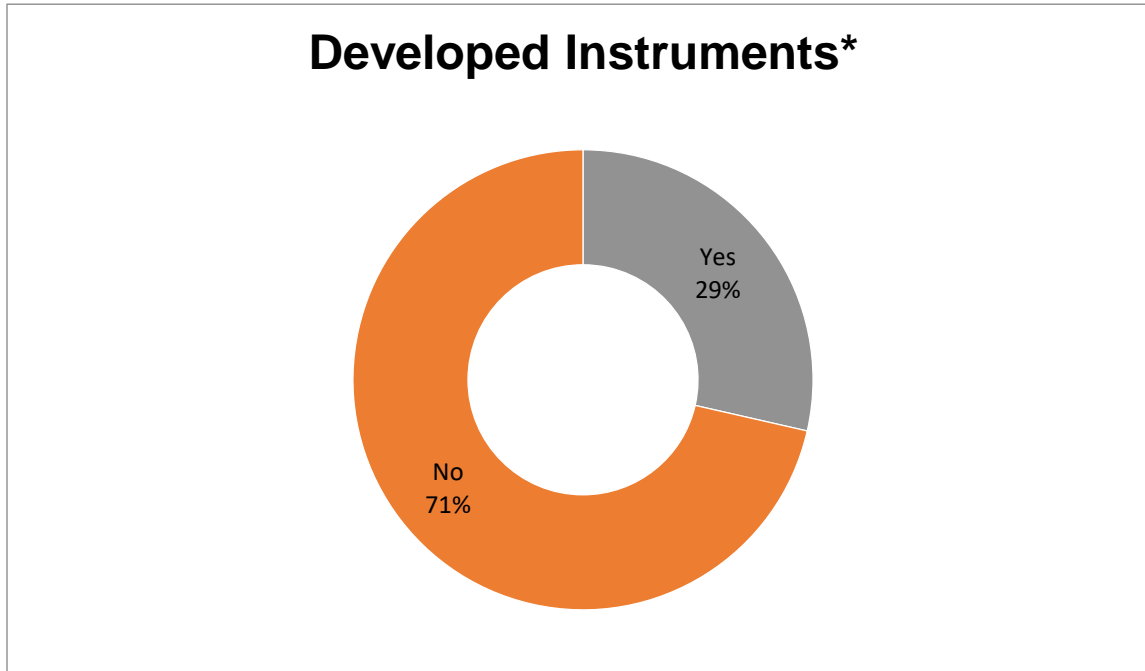


Additional Information from the grants responding Yes:

- **Neuroplastic Adaptations of Swallowing and Speech in Cerebral Palsy: A 2-Center Study to Identify New Treatment Targets.**

Explanation: "An NIH R21 has been awarded to the PI and it is expected that findings from these grants will be conceptually additive."

Grants that Developed Instruments:

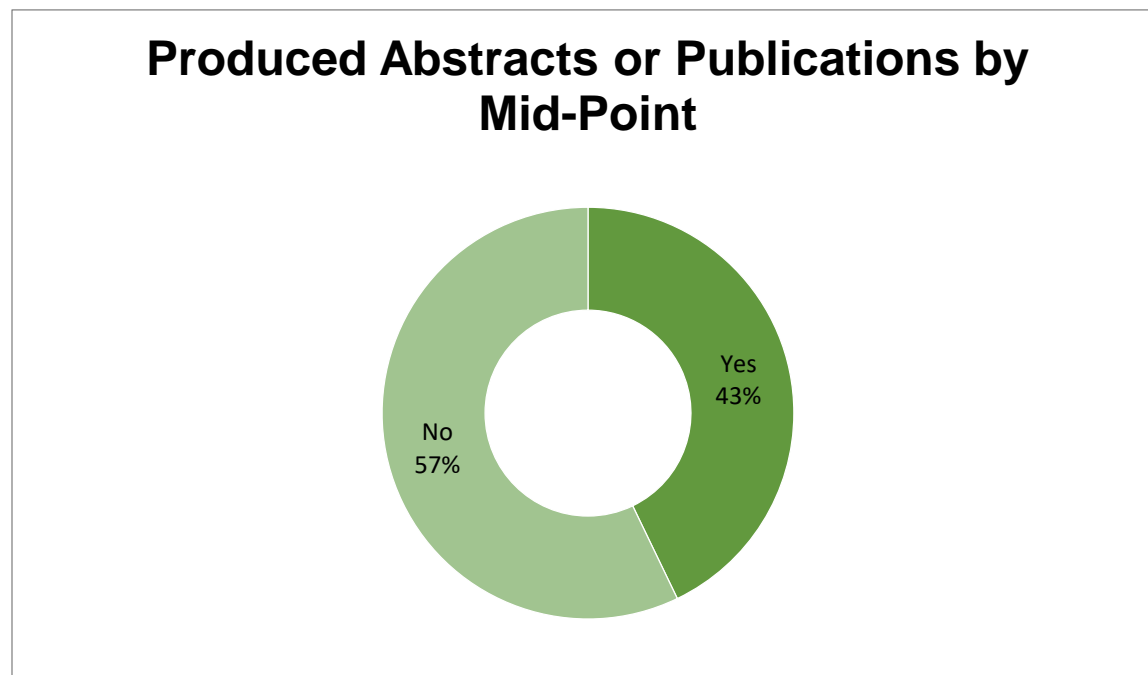


Instruments include: clinical guidelines, clinical outcomes, and clinical tools.

Additional Information from grants responding Yes:

- **Neuroplastic Adaptations of Swallowing and Speech in Cerebral Palsy**
- **Multimorbidity Risk Assessment:** A link to the proposed protocol can be found here: <http://www.comet-initiative.org/studies/details/1130>.

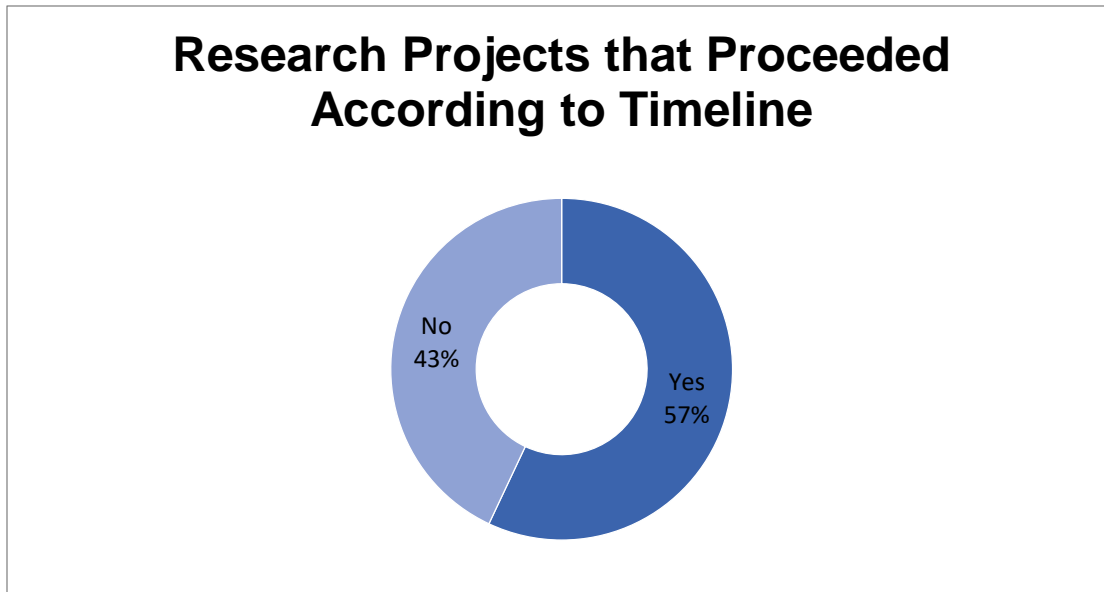
Grants that Produced Abstracts or Publications:



Additional information from grants responding Yes:

- **Biomarkers for Cerebral Palsy-** Manuscript in press in the journal "BMC Bioinformatics" entitled, "Epigenetic Machine Learning: Utilizing DNA Methylation Patterns to Predict Spastic Cerebral Palsy."
- **Neuroplastic Adaptations-** An abstract entitled "New and emerging research directions for the management of feeding and swallowing in CP" that will include preliminary data from this work was accepted and will be presented at the next AACPDm meeting.
- **Multimorbidity Risk Assessment**
 - **Submitted and presented at the 72nd Annual AACPDm meeting:**
 - "Breakfast Seminar: Understanding and preventing multimorbidity in adolescents and adults with cerebral palsy: an emphasis on health-promoting behaviours" at the 72nd Annual AACPDm meeting:
 - Selecting outcome measurement instruments for multimorbidity risk assessment in cerebral palsy: an international Delphi study.
 - Demonstration Poster: Multimorbidity risk assessment and prevention in clinical practice: establishing and testing a core outcome set for adolescents and adults with cerebral palsy.
- **Participation, Mobility, and Gait in Adults with CP-** 2 abstracts submitted as Free Papers at AACPDm Annual Meeting.

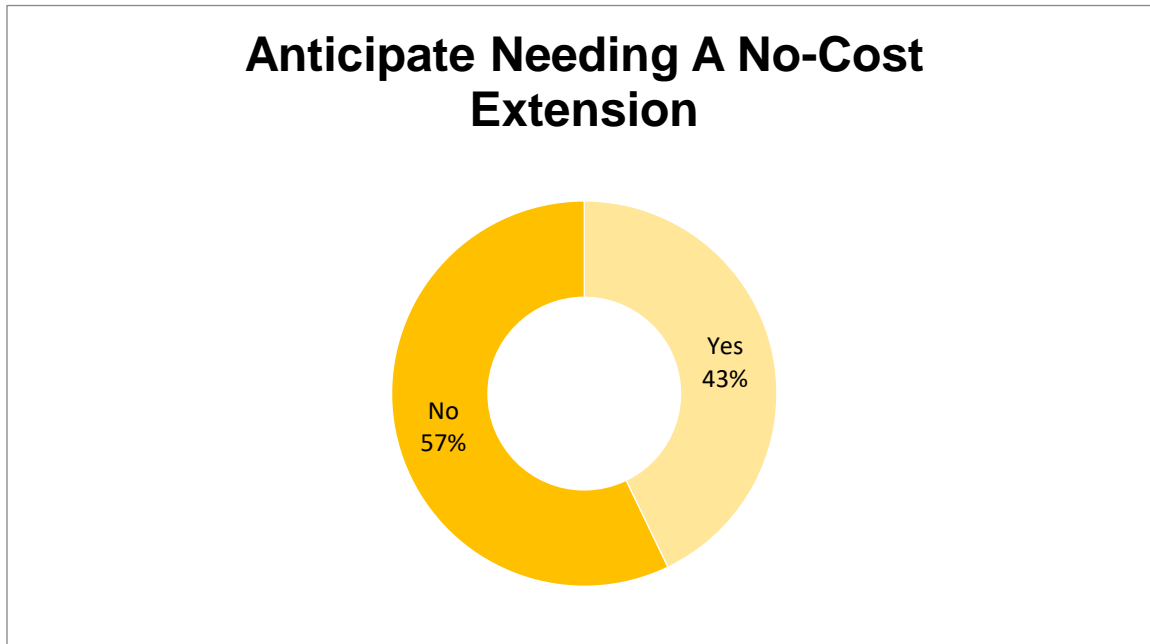
Percentage of Grants that Met Anticipated Timelines:



Additional information for grants responding **No**:

- One replied no because of staffing needs.
- One replied no because of the slow recruitment process.
- One replied no because of delays with their local Institutional Review Board (IRB) approval.

Percentage of Grants that Requested a No-Cost Extension:



Additional information from the grants responding Yes:

- Two needed additional time for data collection.
- One was delayed due to their local Institutional Review Board (IRB) approval.



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