

## Sally Dunaway Young

Neuromuscular Clinical Research Manager/Evaluator, Neurology

### Publications

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#### PUBLICATIONS

- **Development of an International SMA Bulbar Assessment for Inter-professional Administration.** *Journal of neuromuscular diseases*  
Young, S. D., McGrattan, K., Johnson, E., van der Heul, M., Duong, T., Bakke, M., Werlauff, U., Pasternak, A., Cattaneo, C., Hoffman, K., Fanelli, L., Breaks, A., Allison, et al  
2023
- **Assessing Bulbar Function in Spinal Muscular Atrophy Using Patient-Reported Outcomes.** *Journal of neuromuscular diseases*  
Young, S. D., Pasternak, A., Duong, T., McGrattan, K. E., Stranberg, S., Maczek, E., Dias, C., Tang, W., Parker, D., Levine, A., Rohan, A., Wolford, C., Martens, et al  
2023
- **Clinical and Research Readiness for Spinal Muscular Atrophy: The Time Is Now for Knowledge Translation.** *Physical therapy*  
Krosschell, K. J., Young, S. D., Peterson, I., Curry, M., Mazzella, A., Jarecki, J., Cruz, R.  
2022
- **Scoliosis Surgery Significantly Impacts Motor Abilities in Higher-functioning Individuals with Spinal Muscular Atrophy** *JOURNAL OF NEUROMUSCULAR DISEASES*  
Young, S., Montes, J., Salazar, R., Glanzman, A. M., Pasternak, A., Mirek, E., Martens, W., Finkel, R. S., Darras, B. T., De Vivo, D. C.  
2020; 7 (2): 183-192
- **Perceived Fatigue in Spinal Muscular Atrophy: A Pilot Study** *JOURNAL OF NEUROMUSCULAR DISEASES*  
Young, S., Montes, J., Kramer, S. S., Podwika, B., Rao, A. K., De Vivo, D. C.  
2019; 6 (1): 109-117
- **Six-minute walk test is reliable and valid in spinal muscular atrophy** *MUSCLE & NERVE*  
Young, S., Montes, J., Kramer, S. S., Marra, J., Salazar, R., Cruz, R., Chiriboga, C. A., Garber, C., De Vivo, D. C.  
2016; 54 (5): 836-842
- **Physical therapy services received by individuals with spinal muscular atrophy (SMA)** *JOURNAL OF PEDIATRIC REHABILITATION MEDICINE*  
Dunaway, S., Montes, J., McDermott, M. P., Martens, W., Neisene, A., Glanzman, A. M., Pasternak, A., Riley, S., Sproule, D., Chiriboga, C., Finkel, R., Tennekoon, G., Darras, et al  
2016; 9 (1): 35-44
- **PERFORMANCE OF THE TIMED "UP & GO" TEST IN SPINAL MUSCULAR ATROPHY** *MUSCLE & NERVE*  
Dunaway, S., Montes, J., Garber, C., Carr, B., Kramer, S. S., Kamil-Rosenberg, S., Strauss, N., Sproule, D., De Vivo, D. C.  
2014; 50 (2): 273-277
- **Independent Mobility After Early Introduction of a Power Wheelchair in Spinal Muscular Atrophy** *JOURNAL OF CHILD NEUROLOGY*  
Dunaway, S., Montes, J., O'Hagen, J., Sproule, D. M., De Vivo, D. C., Kaufmann, P.  
2013; 28 (5): 576-582
- **Spinal Muscular Atrophy Type III: Trying to Understand Subtle Functional Change Over Time-A Case Report** *JOURNAL OF CHILD NEUROLOGY*  
Dunaway, S., Montes, J., Ryan, P. A., Montgomery, M., Sproule, D. M., De Vivo, D. C.  
2012; 27 (6): 779-785
- **Reliability of telephone administration of the PedsQL (TM) Generic Quality of Life Inventory (TM) and Neuromuscular Module (TM) in spinal muscular atrophy (SMA)** *NEUROMUSCULAR DISORDERS*

- Dunaway, S., Montes, J., Montgomery, M., Battista, V., Koo, B., Marra, J., De Vivo, D. C., Hynan, L. S., Iannaccone, S. T., Kaufmann, P.  
2010; 20 (3): 162-165
- **Onasemnogene abeparvovec preserves bulbar function in infants with presymptomatic spinal muscular atrophy: a post-hoc analysis of the SPRINT trial.** *Neuromuscular disorders : NMD*  
Shell, R. D., McGrattan, K. E., Hurst-Davis, R., Young, S. D., Baranello, G., Lavrov, A., O'Brien, E., Wallach, S., LaMarca, N., Reyna, S. P., Darras, B. T.  
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  - **Measuring Fatigue and Fatigability in Spinal Muscular Atrophy (SMA): Challenges and Opportunities.** *Journal of clinical medicine*  
Rodriguez-Torres, R. S., Uher, D., Gay, E. L., Coratti, G., Dunaway Young, S., Rohwer, A., Muni Lofra, R., De Vivo, D. C., Hirano, M., Glynn, N. W., Montes, J.  
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  - **Patients with Spinal Muscular Atrophy Type 1 Achieve and Maintain Bulbar Function Following Onasemnogene Abeparvovec Treatment.** *Journal of neuromuscular diseases*  
McGrattan, K. E., Shell, R. D., Hurst-Davis, R., Young, S. D., O'Brien, E., Lavrov, A., Wallach, S., LaMarca, N., Reyna, S. P., Darras, B. T.  
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  - **2-Year Change in Revised Hammersmith Scale Scores in a Large Cohort of Untreated Paediatric Type 2 and 3 SMA Participants.** *Journal of clinical medicine*  
Stimpson, G., Ramsey, D., Wolfe, A., Mayhew, A., Scoto, M., Baranello, G., Muni Lofra, R., Main, M., Milev, E., Coratti, G., Pane, M., Sansone, V., D'Amico, et al  
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  - **Exploring Protein Changes in Cerebrospinal Fluid of Spinal Muscular Atrophy Patients Pre-Nusinersen vs. Post-Nusinersen Treatment using Bayesian Machine Learning Algorithms**  
Kamali, T., Hagerman, K., Duong, T., Parker, D., Young, S., Tang, W., Sampson, J., Day, J.  
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  - **Revised upper limb module in type II and III spinal muscular atrophy: 24-month changes.** *Neuromuscular disorders : NMD*  
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  - **Different trajectories in upper limb and gross motor function in spinal muscular atrophy.** *Muscle & nerve*  
Coratti, G., Pera, M. C., Montes, J., Pasternak, A., Scoto, M., Baranello, G., Messina, S., Dunaway Young, S., Glanzman, A. M., Duong, T., de Sanctis, R., Mazzone, E. S., Milev, et al  
2021
  - **Psychometric properties of the PEDI-CAT for children and youth with spinal muscular atrophy.** *Journal of pediatric rehabilitation medicine*  
Fragala-Pinkham, M., Pasternak, A., McDermott, M. P., Mirek, E., Glanzman, A. M., Montes, J., Dunaway Young, S., Salazar, R., Quigley, J., Riley, S. O., Chiriboga, C. A., Finkel, R. S., Tennekoon, et al  
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  - **Advances in the therapy of Spinal Muscular Atrophy.** *The Journal of pediatrics*  
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  - **Nusinersen in pediatric and adult patients with type III spinal muscular atrophy.** *Annals of clinical and translational neurology*  
Pera, M. C., Coratti, G., Bovis, F., Pane, M., Pasternak, A., Montes, J., Sansone, V. A., Dunaway Young, S., Duong, T., Messina, S., Mizzoni, I., D'Amico, A., Civitello, et al  
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Duong, T., Wolford, C., McDermott, M. P., Macpherson, C. E., Pasternak, A., Glanzman, A. M., Martens, W. B., Kichula, E., Darras, B. T., De Vivo, D. C., Zolkipli-Cunningham, Z., Finkel, R. S., Zeineh, et al  
2021; 11 (3): e317-e327
  - **Essential competencies for physical therapist managing individuals with spinal muscular atrophy: A delphi study** *PLOS ONE*  
Timmerberg, J., Krossschell, K. J., Young, S., Uher, D., Yun, C., Montes, J.  
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- **Age related treatment effect in type II Spinal Muscular Atrophy pediatric patients treated with nusinersen.** *Neuromuscular disorders : NMD*  
Coratti, G., Pane, M., Lucibello, S., Pera, M. C., Pasternak, A., Montes, J., Sansone, V. A., Duong, T., Dunaway Young, S., Messina, S., D'Amico, A., Civitello, M., Glanzman, et al  
2021
- **Gaussian Process Regression for COP Trajectory Estimation in Healthy and Pathological Gait Using Instrumented Insoles**  
Duong, T. H., Uher, D., Young, S., Duong, T., Sangco, M., Cornett, K., Montes, J., Zanutto, D., IEEE  
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- **Clinical variability in spinal muscular atrophy type III.** *Annals of neurology*  
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- **Lack of effect on ambulation of dalfampridine-ER (4-AP) treatment in adult SMA patients** *NEUROMUSCULAR DISORDERS*  
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2020; 30 (8): 693-700
- **Quantitative gait assessment in children with 16p11.2 syndrome** *JOURNAL OF NEURODEVELOPMENTAL DISORDERS*  
Goldman, S., McCullough, A. K., Young, S., Mueller, C., Stahl, A., Zoeller, A., Abbruzzese, L., Rao, A. K., Montes, J.  
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- **Nusinersen improves walking distance and reduces fatigue in later-onset spinal muscular atrophy** *MUSCLE & NERVE*  
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2019; 60 (4): 409-414
- **Revised upper limb module for spinal muscular atrophy: 12 month changes** *MUSCLE & NERVE*  
Pera, M., Coratti, G., Mazzone, E. S., Montes, J., Scoto, M., De Sanctis, R., Main, M., Mayhew, A., Lofra, R., Young, S., Glanzman, A. M., Duong, T., Pasternak, et al  
2019; 59 (4): 426-30
- **Quantitative Evaluation of Lower Extremity Joint Contractures in Spinal Muscular Atrophy: Implications for Motor Function** *PEDIATRIC PHYSICAL THERAPY*  
Salazar, R., Montes, J., Young, S., McDermott, M. P., Martens, W., Pasternak, A., Quigley, J., Mirek, E., Glanzman, A. M., Civitello, M., Gee, R., Duong, T., Mazzone, et al  
2018; 30 (3): 209-15
- **Ambulatory function in spinal muscular atrophy: Age-related patterns of progression** *PLOS ONE*  
Montes, J., McDermott, M. P., Mirek, E., Mazzone, E. S., Main, M., Glanzman, A. M., Duong, T., Young, S., Salazar, R., Pasternak, A., Gee, R., De Sanctis, R., Coratti, et al  
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- **Pilot study of population-based newborn screening for spinal muscular atrophy in New York state** *GENETICS IN MEDICINE*  
Kraszewski, J. N., Kay, D. M., Stevens, C. F., Koval, C., Haser, B., Ortiz, V., Albertorio, A., Cohen, L. L., Jain, R., Andrew, S. P., Young, S., LaMarca, N. M., De Vivo, et al  
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- **Ambulatory function and fatigue in nusinersen-treated children with spinal muscular atrophy.**  
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- **Evaluator Training and Reliability for SMA Global Nusinersen TrialsI.** *Journal of neuromuscular diseases*  
Glanzman, A. M., Mazzone, E. S., Young, S. D., Gee, R., Rose, K., Mayhew, A., Nelson, L., Yun, C., Alexander, K., Darras, B. T., Zolkipli-Cunningham, Z., Tennekoon, G., Day, et al

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- **Motor Function Test Reliability During the NeuroNEXT Spinal Muscular Atrophy Infant Biomarker Study.** *Journal of neuromuscular diseases*  
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- **First international workshop on rehabilitation management and clinical outcome measures for spinal muscular atrophy** *NEUROMUSCULAR DISORDERS*  
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- **GAIT ASSESSMENT WITH SOLESOUND INSTRUMENTED FOOTWEAR IN SPINAL MUSCULAR ATROPHY** *MUSCLE & NERVE*  
Montes, J., Zanutto, D., Young, S., Salazar, R., De Vivo, D. C., Agrawal, S.  
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- **Reliability of functional outcome measures in spinal muscular atrophy: Results from multi-centered, global, phase 3 clinical trials**  
Glanzman, A., Mazzone, E., Young, S., Gee, R., Rose, K., Mayhew, A., Yun, C., Alexander, K., Tennekoon, G., Day, J., Finkel, R., Mercuri, E., De Vivo, et al  
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- **Revised Hammersmith Scale for spinal muscular atrophy: A SMA specific clinical outcome assessment tool.** *PLoS one*  
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- **RASCH ANALYSIS OF THE PEDIATRIC EVALUATION OF DISABILITY INVENTORY-COMPUTER ADAPTIVE TEST (PEDI-CAT) ITEM BANK FOR CHILDREN AND YOUNG ADULTS WITH SPINAL MUSCULAR ATROPHY** *MUSCLE & NERVE*  
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- **Developmental milestones in type I spinal muscular atrophy** *NEUROMUSCULAR DISORDERS*  
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2016; 26 (11): 754-759
- **Revised upper limb module for spinal muscular atrophy: Development of a new module.** *Muscle & nerve*  
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- **Characterization of Gait and Fatigue in Children and Adults with Spinal Muscular Atrophy Using Instrumented Footwear**  
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- **Gait Assessment in Children with Known Genetic Neurodevelopmental Disorders with and without Autism Spectrum Disorders**  
Goldman, S., Dunaway, S., Mueller, C., Boehme, A., Sherwood, G., Stahl, A., Zoeller, A., Abbruzzese, L., Rao, A., Montes, J.  
LIPPINCOTT WILLIAMS & WILKINS.2016
- **Patterns of disease progression in type 2 and 3 SMA: Implications for clinical trials** *NEUROMUSCULAR DISORDERS*  
Mercuri, E., Finkel, R., Montes, J., Mazzone, E. S., Sormani, M., Main, M., Ramsey, D., Mayhew, A., Glanzman, A. M., Dunaway, S., Salazar, R., Pasternak, A., Quigley, et al  
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- **SPINAL MUSCULAR ATROPHY FUNCTIONAL COMPOSITE SCORE: A FUNCTIONAL MEASURE IN SPINAL MUSCULAR ATROPHY** *MUSCLE & NERVE*  
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- **Old measures and new scores in spinal muscular atrophy patients** *MUSCLE & NERVE*  
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- **Observational study of spinal muscular atrophy type I and implications for clinical trials** *NEUROLOGY*  
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- **Leg muscle function and fatigue during walking in spinal muscular atrophy type 3** *MUSCLE & NERVE*  
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Montes, J., Garber, C. E., Kramer, S. S., Montgomery, M. J., Dunaway, S., Kamil-Rosenberg, S., Carr, B., Strauss, N. E., Sproule, D., De Vivo, D. C.  
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- **Falls and spinal muscular atrophy: Exploring cause and prevention** *MUSCLE & NERVE*  
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- **Prospective cohort study of spinal muscular atrophy types 2 and 3** *NEUROLOGY*  
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- **Validation of the Children's Hospital of Philadelphia Infant Test of Neuromuscular Disorders (CHOP INTEND)** *PEDIATRIC PHYSICAL THERAPY*  
Glanzman, A. M., McDermott, M. P., Montes, J., Martens, W. B., Flickinger, J., Riley, S., Quigley, J., Dunaway, S., O'Hagen, J., Deng, L., Chung, W. K., Tawil, R., Darras, et al  
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- **Validation of the Expanded Hammersmith Functional Motor Scale in Spinal Muscular Atrophy Type II and III** *JOURNAL OF CHILD NEUROLOGY*  
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