

CURRICULUM VITAE

SUSAN D. APKON, MD
April 2019

PERSONAL DATA:

Current Position: Fischahs Chair in Pediatric Rehabilitation
Children's Hospital Colorado
Visiting Professor, Department of Physical Medicine and Rehabilitation
University of Colorado School of Medicine

Work Address: Children's Hospital Colorado
13123 East 16th Avenue, B285
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EDUCATION:

1982 - 1986 Northwestern University, Evanston, Illinois
Major: Speech-Language Pathology
Degree: Bachelor of Science

1986 – 1987 Northwestern University, Evanston, Illinois
Major: Speech-Language Pathology
Degree: Master of Arts

1990 –1994 University of Vermont College of Medicine, Burlington, Vermont
Degree: Doctor of Medicine

POST GRADUATE TRAINING:

1994 –1995 **Internship:** Pediatrics, University of Colorado,
Department of Pediatrics
Denver, Colorado

1995 – 1999 **Residency:** Pediatrics and Physical Medicine and Rehabilitation,
University of Colorado, Departments of Pediatrics and Physical
Medicine and Rehabilitation
Denver, Colorado

2000- 2001 **Research Fellowship:** Missouri Arthritis Rehabilitation
Research and Training Center, University of Missouri
Columbia, Missouri

ACADEMIC APPOINTMENTS:

1999- 2005 Assistant Professor, Department of Physical Medicine and Rehabilitation, University of Colorado, Denver, Colorado

2005- 2009 Associate Professor, Department of Physical Medicine and Rehabilitation, University of Colorado, Aurora, Colorado

2007- 2009 Program Director, Rehabilitation Medicine Residency
University of Colorado, Aurora, Colorado

2009- 2015 Associate Professor, Department of Rehabilitation Medicine,
University of Washington, Seattle, Washington

2010- 2014 Program Director, Pediatric Rehabilitation Medicine Fellowship
University of Washington, Seattle, Washington

2015 -2018 Professor, Department of Rehabilitation Medicine
University of Washington, Seattle, Washington

2019- Visiting Professor, Department of Physical Medicine and Rehabilitation
University of Colorado, Aurora, Colorado

HOSPITAL POSITIONS:

1999- 2009 Attending Physician, The Children’s Hospital (Colorado)
Aurora, Colorado

1999- 2009 Consulting Physician, Memorial Hospital
Colorado Springs, Colorado

2000- 2009 Consulting Physician, Northern Colorado Medical Center
Greeley, Colorado

2000- 2009 Consulting Physician, University of Colorado Hospital
Aurora, Colorado

2001- Present Consulting Physician, St. Vincent’s Hospital,
Billings, Montana

2007- 2009 Consulting Physician, Denver Health Medical Center
Denver, Colorado

2009-2018 Director, Department of Rehabilitation Medicine
Seattle Children’s Hospital, Seattle, Washington

2019- Chief, Department of Rehabilitation
Children’s Hospital Colorado, Aurora, Colorado

HONORS AND AWARDS:

2006	Outstanding Teaching Award Department of Physical Medicine and Rehabilitation University of Colorado
2006, 2007, 2008 2011, 2012, 2013, 2014, 2015 2016, 2017	5280 Top Doctor Denver Seattle Magazine Top Doctor
2013	Seattle Children's Family Choice Award
2013	Rod & Randy Halvorson Award, Muscular Dystrophy Association Seattle, Washington
2015	Distinguished Clinician Award, American Academy of Physical Medicine and Rehabilitation, Boston, MA
2017	Outstanding Council Service Award, Pediatric Rehabilitation/Developmental Disabilities Council, American Academy of Physical Medicine and Rehabilitation, Denver, CO

PROFESSIONAL MEMBERSHIPS:

1982- 1994	American Speech and Hearing Association
1994- 2002, 2017-Present	American Academy of Pediatrics
1996- Present	American Academy of Physical Medicine and Rehabilitation
2006- 2017	American Academy of Cerebral Palsy and Developmental Medicine
2018- Present	World Muscle Society

SPECIAL NATIONAL RESPONSIBILITIES:

2002- 2008	Pediatric Rehabilitation Subspecialty Board Examination Writer, American Board of Physical Medicine and Rehabilitation
2004- Present	Oral Board Examiner, American Board of Physical Medicine and Rehabilitation
2008- Present	Pediatric Rehabilitation Subspecialty Board Examination, Associate Director, American Board of Physical Medicine and Rehabilitation
2016-Present	Vignette writer for the Part II (oral) Examination, American Board of Physical Medicine and Rehabilitation

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2009-2015	CureSMA Medical Advisory Committee
2012-2015	Pediatrics Council, Vice-Chair of Communications American Academy of Physical Medicine and Rehabilitation
2013-Present	Muscular Dystrophy Association Clinical Advisory Committee
2013-Present	Parent Project Muscular Dystrophy Duchenne Care Clinics/Centers Accreditation Committee
2017-Present	Executive Committee of the Council on Children with Disabilities American Academy of Pediatrics

SPECIAL LOCAL RESPONSIBILITIES:

2000-2002	Medical Staff Nominating Committee, The Children's Hospital (Colorado)
2002-2009	Physician Review Team, The Children's Hospital (Colorado)
2005-2009	Multi-disciplinary Trauma Committee, The Children's Hospital (Colorado)
2008- 2009	Medical Staff Board, Secretary/Treasurer, The Children's Hospital (Colorado)
2008- 2009	Quality and Patient Safety Committee, The Children's Hospital (Colorado)
2008-2009	Medical Executive Committee, The Children's Hospital (Colorado)
2009- Present	Medical Executive Committee, Seattle Children's Hospital
2009- Present	Hospital Steering Committee, Seattle Children's Hospital
2011-Present	CUMG Board Member
2012-2013	Chair, Dental Director Recruitment Committee, Seattle Children's Hospital
2014	Orthopedic Director Recruitment Committee, Seattle Children's Hospital
2014-2016	Pediatric Partners in Care (PPIC) Clinical Leadership Committee, Seattle Children's Hospital
2017	Mentoring Committee, University of Washington Department of Rehabilitation Medicine

BOARD CERTIFICATION:

2000	American Board of Pediatrics, Recertified 2007, 2013
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- 2000 American Board of Physical Medicine and Rehabilitation,
Recertified 2010
- 2003 American Board of Physical Medicine and Rehabilitation,
Subspecialty Certification in Pediatric Rehabilitation
Recertified, 2010, 2018

CURRENT LICENSES:

- 1996- Present Physician, State of Colorado
- 2002- Present Physician, State of Montana
- 2009- Present Physician, State of Washington

EDITORIAL RESPONSIBILITIES:

- 2008- Present PM&R The Journal of Injury, Function, and Rehabilitation
Associate Editor

PRESENTATIONS

International Invitational Lectures:

- 2/2007 “Topics in Pediatric Rehabilitation”, Annual Meeting of the Nicaraguan Society of
Rehabilitation Physicians, Managua, Nicaragua
- 11/2007 “Care of the Child with Cerebral Palsy”, Aldo Chevarria National Rehabilitation
Hospital, Managua, Nicaragua
- 11/2015 “Spasticity Management in a Child with Cerebral Palsy”, United Family Healthcare, Beijing,
China
- 11/2015 “Duchenne Muscular Dystrophy: Update on Care”, United Family Healthcare, Beijing,
China
- 11/2015 “CP: The Multidisciplinary Approach to Care”, Shanghai Children’s Hospital, Shanghai,
China
- 10/2017 “Care in the Era of Spinraza”, Nordic Neurology Conference, Stockholm, Sweden
- 10/2017 “Building a Successful Treatment Program,” Nordic Neurology Conference, Stockholm,
Sweden

National Invitational Lectures (past 10 years):

- 6/2008 “Non-operative management of children with SMA”, Families of SMA Annual

- Meeting, Boston, MA
- 7/2008 “High-risk Spine Pathway, Duchenne Muscular Dystrophy”, Parent Project Muscular Dystrophy Annual Meeting, Philadelphia, PA
- 12/2009 “Outcomes after Pediatric Abusive Head Trauma”, Pediatric Trauma Conference, Denver, CO
- 6/2010 “The Role of Rehabilitation Medicine in the Care of Children with SMA, Families of SMA Annual Meeting, Cincinnati, OH
- 6/2011 “Musculoskeletal Issues in children with Type II and III SMA”, Families of SMA Annual Meeting, Orlando, FL
- 6/2012 “Goals, Roles and Referrals: Motor Function”, Interdisciplinary Perspectives on Spinal Muscular Atrophy: Defining Your Role, Minneapolis MN
- 6/2012 “Musculoskeletal Issues in children with Type II and III SMA”, Families of SMA Annual Meeting, Orlando, FL
- 5/2013 “Transitioning young adults with Duchenne Muscular Dystrophy”, Parent Project Muscular Dystrophy West Coast Connect meeting, San Diego, CA
- 6/2013 “Medical Watershed Moments”, Parent Project Muscular Dystrophy Transition Meeting, Baltimore, MD
- 6/2013 “Goals, Roles and Referrals: Motor Function”, Interdisciplinary Perspectives on Spinal Muscular Atrophy: Defining Your Role, Anaheim, CA
- 5/2014 “Duchenne Muscular Dystrophy: Treatment Updates”, Fourth Biennial Pediatric Neurosciences Conference. Minneapolis, MN
- 7/2014 “Duchenne Care and Management: Age 15 and Up”, Parent Project Muscular Dystrophy 2014 Annual Conference, Chicago IL.
- 7/2014 “Strength Happens Together: A Panel Discussion”, Parent Project Muscular Dystrophy 2014 Annual Conference, Chicago IL.
- 6/2015 “Newly Diagnosed: Spinal Muscular Atrophy type II and III”, CureSMA 2015 Annual Conference, Kansas City, MO.
- 6/2015 “Therapy and Musculoskeletal Issues in Spinal Muscular Atrophy type II and III.” CureSMA 2015 Annual Conference, Kansas City, MO.
- 3/2016 “Rehabilitation Principles in Neuromuscular Diseases: Maximizing Function in Children”, MDA Annual Clinic Conference, Arlington, VA.
- 7/2017 “Diagnosis and Use of Steroids in Ambulatory Boys with DMD”, Parent Project Muscular Dystrophy 2017 Annual Conference, Chicago IL.
- 7/2017 “Fat Embolism Syndrome in Boys with DMD”, Parent Project Muscular Dystrophy 2017 Annual Conference, Chicago IL.

- 10/2017 “Bone Health: Vitamin D, Calcium, Bone Density and Osteopenia in Childhood Disability”, Pediatric Rehabilitation Conference. Children’s Hospital Colorado, Aurora, CO.
- 11/2017 “Clinical Trials and Research Overview: Duchenne Muscular Dystrophy”, ESO Conference, Parent Project Muscular Dystrophy, Albuquerque, NM.
- 3/2018 “Primary and Secondary Prevention of Fractures in Neuromuscular Conditions”, Muscular Dystrophy Association Annual Clinical Conference, Arlington, VA
- 8/2018 “Spinal Muscular Atrophy – Novel Treatments and Their Ethical Quagmires” Distinguished Lecture: TIRR, Houston Texas

National Presentations (past 10 years):

- 9/2008 “Osteoporosis in People with Disabilities”, Department of Rehabilitation Medicine University of Washington, Seattle, WA
- 11/2009 “Rehabilitation in the Child with a Spinal Cord Tumor”, American Academy of Physical Medicine and Rehabilitation Medicine Annual Meeting, Austin, TX
- 11/2010 “Top 10 Articles of the Past Year”, American Academy of Physical Medicine and Rehabilitation Annual Meeting, Seattle, WA
- 11/2011 “Top 10 Articles of the Past Year”, American Academy of Physical Medicine and Rehabilitation Annual Meeting, Orlando, FL
- 11/2012 “Top 10 Articles of the Past Year”, American Academy of Physical Medicine and Rehabilitation Annual Meeting, Orlando, FL
- 11/2013 “Top 10 Articles of the Past Year”, American Academy of Physical Medicine and Rehabilitation Annual Meeting, Washington DC.
- 11/2014 “Influence of Activity on Bone Health in Children with Cerebral Palsy”, American Academy of Cerebral Palsy and Developmental Medicine Annual Meeting, San Diego, CA
- 10/2017 “Spinal Muscular Atrophy: an update on the new hope that has arrived for SMA”, American Academy of Physical Medicine and Rehabilitation Annual Meeting, Denver, CO
- 10/2017 “Update on the 2017 CDC Duchenne Muscular Dystrophy Care Guidelines”, American Academy of Physical Medicine and Rehabilitation Annual Meeting, Denver, CO

Local and Regional Presentations (past 10 years):

- 1/2008 “Orthopedic Issues in Children with Cerebral Palsy”, St. Vincent’s Hospital, Billings, MT
- 8/2008 “Spinal Muscular Atrophy”, Genetics Grand Rounds, University of Colorado School of Medicine, Aurora, CO

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- 12/2009 “Spasticity Management in Children with Cerebral Palsy”, University of Washington, Department of Pediatrics, Division of Developmental Medicine, Seattle, WA
- 2/2010 “Emergency Room Visits for Children with Intrathecal Baclofen Pumps”, University of Washington Department of Pediatrics, Division of Emergency Medicine, Seattle, WA
- 3/2010 “Acute Care Issues in Children with Disabilities”, North Pacific Pediatric Society 180th Scientific Conference, Seattle, WA
- 3/2010 “Maximizing Mobility through Adaptation and Innovation”, 31st Annual Duncan Seminar, Seattle, WA
- 9/2010 “Spasticity Management in Children with Cerebral Palsy”, Pediatric Special Interest Group, Pacific NW PT Society, Seattle, WA
- 12/2010 “Evaluation of the Hypotonic Child”, University of Washington, Department of Pediatrics, Division of Neurodevelopmental Medicine, Seattle, WA
- 2/2011 “Duchenne Muscular Dystrophy, Diagnosis, Management, and Insights”, Seattle Children’s Grand Rounds, Seattle, WA
- 5/2011 “Rehabilitation: The Short and Long Road”, WAMI Regional Brain Injury Conference, Seattle, WA
- 6/2011 “Case Presentation: SEPN1 Congenital Muscular Dystrophy”, MDA Pacific Northwest Clinic Directors Meeting, Portland, OR
- 1/2012 “Reducing Hospital Acquired Fractures, the Team Approach”, Seattle Children’s Hospital Patient Safety Rounds, Seattle, WA
- 11/2012 “CP – the Rehabilitation Perspective”, Madigan Army Hospital, Division of Neurodevelopmental Medicine, Tacoma, WA
- 1/2013 “CP – making good decisions with a challenging diagnosis”, Seattle Children’s Hospital Grand Rounds, Seattle WA
- 3/2013 “Orthopedic issues in the child with CP”, 2013 Duncan Seminar, Seattle Children’s Hospital, Seattle, WA
- 1/2014 “Gait abnormalities: a neurological cause”, 2014 Staheli Conference, Seattle Children’s Hospital, Seattle WA
- 2/2015 “This Child is at Risk for Fracture: Identifying and managing the child with fragile bones in the primary care office”, 2015 Practical Pediatrics, Seattle Children’s Hospital, Seattle, WA
- 2/2015 “Common Issues in Pediatric Rehabilitation Medicine: Cases for the Primary Care Physician”, 2015 Practical Pediatrics, Seattle Children’s Hospital, Seattle, WA
- 5/2015 “Comprehensive Care of the Boy with Duchenne Muscular Dystrophy”, 2015 PPMD Pacific NW Regional Conference, Seattle Children’s Hospital, Seattle, WA

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- 5/2016 “Duchenne Muscular Dystrophy: A Changing Landscape”, Lehmann Day, University of Washington Department of Rehabilitation Medicine, Seattle, WA
- 7/2016 “Spinal Muscular Atrophy: Diagnosis and Treatment”, Grand Rounds, Neurodevelopmental Medicine, Seattle Children’s Hospital, Seattle, WA
- 3/2017 “Research Update: Duchenne muscular dystrophy”, Parent Project Muscular Dystrophy Every Single One Regional Conference, Seattle, WA
- 9/2017 “Update on Novel Treatments for SMA and DMD”, University of Washington Department of Pediatrics, Division of Biochemical Genetics, Seattle, WA
- 11/2017 “Update on the SMA Treatment Program”, Surgical Services, Seattle Children’s Hospital, Seattle, WA
- 1/2018 “SMA, the Novel Treatments and Ethical Quagmires that Surround Them”, Seattle Children’s Grand Rounds, Seattle, WA

TEACHING RESPONSIBILITIES:

- 2009-2018 Department of Pediatrics
University of Washington, Seattle, Washington
1 lecture hour/year
- 2009-2018 Department of Rehabilitation Medicine
University of Washington, Seattle, Washington
12 lecture hours/year: Residency
12 lecture hours/year: Pediatric Rehabilitation Fellowship
- 2010-2018 Department of Rehabilitation Medicine
University of Washington, Seattle, Washington
Rehabilitation Sciences, Course 400
3 lecture hours/year

RESEARCH FUNDING:

- 2002-2009 Co-Investigator (15% time), Surveillance and Epidemiologic Research of Duchene and Becker Muscular Dystrophy and Other Single Gene Disorders, Centers for Disease Control and Prevention, Grant number: U50/CCU822319, PI Dennis Matthews, MD
- 2003-2009 Principal Investigator, Use of Alendronate in Boys with Duchenne Muscular Dystrophy, Sponsors: The Children’s Hospital Research Institute & Merck & Co., Inc
- 2007- 2008 Principal Investigator, Reproducibility of DXA measurements of the distal femur and lumbar spine in children with non-ambulatory cerebral palsy, F. Hoffmann-La Roche Ltd

- 2008-2009 Local Principal Investigator, A Phase 2b Efficacy and Safety Study of PTC124 in Subjects with Nonsense-Mutation-Mediated Duchenne and Becker Muscular Dystrophy, Sponsor: PTC Therapeutics
- 2011-2015 Principal Investigator, Impact of walking activity on bone health in children with cerebral palsy, Academic Enrichment Fund, Seattle Children's Hospital, Study Budget \$40,000
- 2012-2012 Local Principal Investigator, A Phase 1, Multi-center, Controlled, Prospective Correlative Study of Electrical Impedance Myography in Males with Duchenne Muscular Dystrophy and in Healthy Males, Sponsor: Holloran
- 2012-2014 Local Principal Investigator, BOTOX® Treatment in Pediatric Upper Limb Spasticity: Double-blind Study, Sponsor: Allergan Pharmaceuticals
- 2012-2014 Local Principal Investigator, BOTOX® Treatment in Pediatric Lower Limb Spasticity: Double-blind Study, Sponsor: Allergan Pharmaceuticals
- 2012-2014 Local Principal Investigator, Duchenne Long – Term Idebenone Study (DELOS): A phase III double blind, randomized, placebo – controlled study of the efficacy, safety and tolerability of idebenone in 10 – 18-year-old patients with Duchenne Muscular Dystrophy, Sponsor: Santhera Pharmaceuticals
- 2013-2018 Local Principal Investigator, A Phase 3 Efficacy and Safety Study of Ataluren (PTC 124) in patients with nonsense mutation dystrophinopathy. Sponsor: PTC Therapeutics
- 2014-2016 Local Principal Investigator, A Randomized, Double-Blind, Placebo-Controlled, Phase 3 Trial of Tadalafil for Duchenne muscular dystrophy (H6D-MC-LVJJ), Sponsor: Eli Lilly and Company
- 2016-2017 Local Principal Investigator, An open label, expanded access protocol intended to provide treatment with MP-104 (deflazacort) to U.S. children, adolescents, and/or adults with Duchenne muscular dystrophy, Sponsor: Marathon Pharmaceuticals, LLC
- 2014-2018 Local Principal Investigator, An Open – Label, Multi – Center, 48 – Week Study with a Concurrent Untreated Control Arm to Evaluate the Efficacy and Safety of Eteplirsen in Duchenne Muscular Dystrophy, Sponsor: Sarepta Therapeutics
- 2014-2018 Local Principal Investigator, An Open-Label, Multi-Center Study to Evaluate the Safety and Tolerability of Eteplirsen in Patients with Advanced State Duchenne Muscular Dystrophy, Sponsor: Sarepta Therapeutics
- 2017-2018 Local Principal Investigator, A phase 3, randomized, double-blind, placebo-controlled efficacy and safety study of ataluren in patients with nonsense mutation Duchenne muscular dystrophy and open label extension. (Protocol PTC124-GD-041-DMD). Sponsor: PTC Therapeutics
- 2015-2018 Medtronic Product Surveillance Registry, Sponsor: Medtronic

- 2015-2018 Local Principal Investigator, An Open-Label, Multi-Center Study to Evaluate the Safety, Efficacy and Tolerability of Eteplirsen in Early-Stage Duchenne Muscular Dystrophy, Sponsor: Sarepta Therapeutics
- 2015-2018 Local Co-Investigator, A phase 2, randomized, double-blind, sham-procedure controlled study to assess the safety and tolerability and explore the efficacy of ISIS 396443 (BIIB058) administered intrathecally in subjects with spinal muscular atrophy who are not eligible to participate in the clinical studies ISIS 396443-CS3B or ISIS 396443-CS4

BIBLIOGRAPHY:

Manuscripts in Refereed Journals:

1. **Apkon SD**, Osteoporosis in children who have disabilities. *Physical Medicine and Rehabilitation Clinics of North America*. Turk M. editor. 2002; 13(4): 839-855. PMID:12465563.
2. Oleszek J, Chang N, **Apkon SD**, and Wilson PE. The use of botulinum toxin type A in the treatment of children with congenital muscular torticollis. *Am Journal of Phys Med Rehab*, 2005;84:813-816. PMID:16205437.
3. **Apkon, SD** and Coll J. Use of Weekly Alendronate to Treat Osteoporosis in Boys with Muscular Dystrophy. *Am J Phys Med Rehab*, 2008; 87:139-43. PMID:17912140.
4. **Apkon SD**, Fenton L, and Coll J. Bone Mineral Density in Children with Myelomeningocele. *Dev Med Child Neurol*, 2008; 51:63-67. PMID:18811711.
5. **Apkon, SD** and Kecskemethy HH. Bone Health in Children with Cerebral Palsy. *Journal of Pediatric Rehabilitation Medicine*. 2008; 1(2): 115-121. PMID:21791754.
6. Bernard TJ, Fenton LZ, **Apkon SD**, et al. Biomarkers of Hypercoagulability and Inflammation in Childhood-Onset Arterial Ischemic Stroke. *J Pediatr*, 2009; 156(4):651-6. PMID:20022340.
7. **Apkon SD**, Cassidy D. Safety of Botulinum toxin in Children with Cerebral Palsy. *PM&R*, 2010 Apr;2(4):282-284. PMID:20430330.
8. Arias R, Andrews J, Pandya S, Petit K, Trout C, **Apkon S**, et al. Palliative care services in families of males with Duchenne muscular dystrophy. *Muscle Nerve*. 2011 July;44(1);93-101. PMID:21674523.
9. Wang CH, Dowling JJ, North K, Schroth MK, Sejersen T, Shapiro F, Bellini J, Weiss H, Guillet M, Amburgey K, **Apkon S** et al. Consensus statement on standard of care for congenital myopathies. *J Child Neurol*. 2012 Mar;27(3):363-82. PMID: 22431881.
10. **Apkon SD**. Moving forward: exercise as an intervention to improve bone health in children with disabilities. *Dev Med Child Neurol*. 2012 June; 54(6):490-1. PMID: 22428964.
11. Zumsteg JM, Ennis SK, Jaffe KM, Mangione-Smith R, MacKenzie EJ, Rivara FP; **National Expert Panel for the Development of Pediatric Rehabilitation Quality of Care Indicators**. Quality of care indicators for the structure and organization of inpatient rehabilitation care of children with traumatic brain injury. *Arch Phys Med Rehabil*. 2012 Mar;93(3):386-93. PMID 22280893.

12. Rivara FP, Ennis SK, Mangione-Smith R, MacKenzie EJ, Jaffe KM; **National Expert Panel for the Development of Pediatric Rehabilitation Quality Care Indicators**. Quality of care indicators for the rehabilitation of children with traumatic brain injury. *Arch Phys Med Rehabil*. 2012 Mar;93(3):381-5. PMID:22280892.
13. **Apkon S**. Bone mineral density in children with congenital spinal dysfunction: updated technology for an old issue. *Dev Med Child Neurol*. 2012 Dec; 54(12):1077. PMID:23163816.
14. Pettygrove S, Lu Z, Andrews JG, Meaney FJ, Sheehan DW, Price ET, Fox DJ, Pandya S, Ouyang L, **Apkon SD**, Powis Z, Cunniff C. Sibling concordance for clinical features of Duchenne and Becker muscular dystrophies. *Muscle Nerve*. 2013; Jun 49(6):814-21. PMID: 24030636.
15. McDonald CM, Henricson EK, Abresch RT, Florence JM, Eagle M, Gappmaier E, Glanzman AM; **PTC124-GD-007-DMD Study Group**, Spiegel R, Barth J, Elfring G, Reha A, Peltz S. The 6-minute walk test and other endpoints in Duchenne muscular dystrophy: longitudinal natural history observations over 48 weeks from a multicenter study. *Muscle Nerve*. 2013 Sep;48(3):343-56. PMID: 23681930
16. McDonald CM, Henricson EK, Abresch RT, Florence J, Eagle M, Gappmaier E, Glanzman AM; **PTC124-GD-007-DMD Study Group**, Spiegel R, Barth J, Elfring G, Reha A, Peltz SW. The 6-minute walk test and other clinical endpoints in duchenne muscular dystrophy: reliability, concurrent validity, and minimal clinically important differences from a multicenter study. *Muscle Nerve*. 2013 Sep; 48(3):357-68. PMID: 23674289
17. North KN, Wang CH, Clarke N, Jungbluth H, Vainzof M, Dowling JJ, Amburgey K, Quijano-Roy S, Beggs AH, Sewry C, Laing NG, Bönnemann CG; **International Standard of Care Committee for Congenital Myopathies**. Approach to the diagnosis of congenital myopathies. *Neuromuscul Disord*. 2014 Feb;24(2):97-116. PMID: 24456932
18. **Apkon SD**, Grady R, Hart S, Lee A, McNalley T, Niswander L, Peterson J, Remley S, Rotenstein D, Shurtleff H, Warner M, and Walker W. Advances in the care of children with spina bifida. *Adv Pediatr*. 2014 Aug;61(1):33-74. PMID: 25037124.
19. Ness K, **Apkon SD**. Bone Health in Children with Neuromuscular Disorders. *J Pediatr Rehabil Med*. 2014 Jan 1;7(2):133-42. PMID: 25096865.
20. James KA, **Apkon SD**, Miller L, Mathews K, Cunniff C, Lu Z, Holtzer C, Pandya S, and Cialfoni E , Risk Factors for First Fractures among Males with Duchenne or Becker Muscular Dystrophy. *J Pediatr Orthop*. 2014 Nov 6. PMID: 25379822.
21. Zaidman C, Wang L, Connolly A, Florence J, Wong B, Parsons J, **Apkon S**, Goyal N, Williams E, Escolar D, DART-EIM Clinical Evaluators Consortium, Bohorquez J. Electrical Impedance Myography in Duchenne Muscular Dystrophy and Healthy Controls: A Multi-Center Study of Reliability and Validity. *Muscle Nerve*. 2015 Feb 20. PMID: 25702806.
22. Jimenez N, Osorio M, Ramos JL, **Apkon S**, Ebel BE, Rivara FP. Functional Independence after Inpatient Rehabilitation for Traumatic Brain Injury among Minority Children and Adolescents. *Arch Phys Med Rehabil*. 2015 Mar 4. PMID: 25702806.

23. Buyse GM, Voit T, Schara U, Straathof CS, D'Angelo MG, Bernert G, Cuisset JM, Finkel RS, Goemans N, McDonald CM, Rummey C, Meier T; **DELOS Study Group**. Efficacy of idebenone on respiratory function in patients with Duchenne muscular dystrophy not using glucocorticoids (DELOS): a double-blind randomised placebo-controlled phase 3 trial. *Lancet*. 2015 May 2;385(9979):1748-57. PMID: 25907158.
24. Tsao E, Bjornson K, Christensen A, **Apkon S**. Functional Outcomes and Unplanned Transfers of Pediatric Patients With Central Neurological Impairments Receiving Inpatient Rehabilitation Care With Cancer and Noncancer Diagnoses. *PM R*. 2015 Oct 26. S1934-1482(15)01085-0. PMID: 26514788.
25. Fuentes MM, **Apkon S**, Jimenez N, Rivara FP. Association between facility type During Pediatric Inpatient Rehabilitation and Functional Outcomes. *Arch Phys Med Rehabil*. 2016 Mar 26 (ahead of print.) PMID: 27026580.
26. **Apkon S**, Weiss L, Roth EJ, Mukherjee D. Cases That “Stick” or Stay With Us. *PM R*. 2016 Apr;8(4):367-72. PMID:27068555.
27. McDonald CM, Meier T, Voit T, Schara U, Straathof CS, D'Angelo MG, Bernert G, Cuisset JM, Finkel RS, Goemans N, Rummey C, Leinonen M, Spagnolo P, Buyse GM; **DELOS Study Group**. Idebenone reduces respiratory complications in patients with Duchenne muscular dystrophy. *Neuromuscul Disord*. 2016 Aug;26(8):473-80. PMID: 27238057.
28. Fuentes MM, Jimenez N, **Apkon SD**, Rivara FP. Functional outcomes during inpatient rehabilitation for American Indian and Alaska Native children with traumatic brain injury. *J Pediatr Rehabil Med*. 2016 May 31;9(2):133-41. PMID:27285806.
29. Fuentes MM, Bjornson K, Christensen A, Harmon R, **Apkon SD**. Disparities in Functional Outcomes during Inpatient Rehabilitation between American Indian/Alaska Native and White Children. *J Health Care Poor Underserved*. 2016;27(3):1080-96. PMID: 27524753.
30. Bales J, **Apkon S**, Osorio M, Kinney G, Robison RA, Hooper E, Browd S. Infra-Conus Single-Level Laminectomy for Selective Dorsal Rhizotomy: Technical Advance. *Pediatr Neurosurg*. 2016 Aug 23. PMID: 27548353.
31. Hollin IL, Peay HL, **Apkon SD**, Bridges JF. Patient-centered benefit-risk assessment in duchenne muscular dystrophy. *Muscle Nerve*. 2016 Sep 20. PMID:27649378.
32. Kornafel T, Tsao EY, Sabelhaus E, Surges L, **Apkon SD**. Physical and Occupational Therapy for a Teenager with Acute Flaccid Myelitis: A Case Report. *Phys Occup Ther Pediatr*. 2017 Jan 17:1-11. PMID: 28095134.
33. Fuentes MM, Thompson L, Quistberg DA, Haaland WL, Rhodes K, Kartin D, Kerfeld C, **Apkon S**, Rowhani-Rahbar A, Rivara FP. Auditing access to outpatient rehabilitation services for children with traumatic brain injury and public insurance in Washington State. *Arch Phys Med Rehabil*. 2017 Jan 23. (17)30015-1. PMID: 28126353.
34. Hanak BW, Tomyzc L, Oxford RG, Hooper E, **Apkon SD**, Browd SR. An algorithmic approach to the management of unrecognized hydrocephalus in pediatric candidates for intrathecal baclofen pump implantation. *Surg Neurol Int*. 2016 Dec 20;7:105. PMID: 28168091.
35. Meier T, Rummey C, Leinonen M, Spagnolo P, Mayer OH, Buyse GM; **DELOS Study Group**.

Characterization of pulmonary function in 10-18 year old patients with Duchenne muscular dystrophy. *Neuromuscul Disord*. 2017 Jan 6. PMID: 28189481.

36. Victor RG, Sweeney HL, Finkel R, McDonald CM, Byrne B, Eagle M, Goemans N, Vandeborne K, Dubrovsky AL, Topaloglu H, Miceli MC, Furlong P, Landry J, Elashoff R, Cox D; **Tadalafil DMD Study Group**. A phase 3 randomized placebo-controlled trial of tadalafil for Duchenne muscular dystrophy. *Neurology*. 2017 Sep 29. PMID: 28972192.

37. McDonald CM, Campbell C, Torricelli RE, Finkel RS, Flanigan KM, Goemans N, Heydemann P, Kaminska A, Kirschner J, Muntoni F, Osorio AN, Schara U, Sejersen T, Shieh PB, Sweeney HL, Topaloglu H, Tulinius M, Vilchez JJ, Voit T, Wong B, Elfring G, Kroger H, Luo X, McIntosh J, Ong T, Riebling P, Souza M, Spiegel RJ, Peltz SW, Mercuri E; Clinical Evaluator Training Group; **ACT DMD Study Group**. Ataluren in patients with nonsense mutation Duchenne muscular dystrophy (ACT DMD): a multicentre, randomised, double-blind, placebo-controlled, phase 3 trial. *Lancet*. 2017 Sep 23;390(10101):1489-1498. PMID: 28728956.

38. Weaver JJ, Natarajan N, Shaw DWW, **Apkon SD**, Koo KSH, Shivaram GM, Monroe EJ. Transforaminal intrathecal delivery of nusinersen using cone-beam computed tomography for children with spinal muscular atrophy and extensive surgical instrumentation: early results of technical success and safety. *Pediatr Radiol*. 2017 Nov 13. PMID 29130140.

39. Birnkrant DJ, Bushby K, Bann CM, **Apkon SD**, Blackwell A, Brumbaugh D, Case LE, Clemens PR, Hadjiyannakis S, Pandya S, Street N, Tomezsko J, Wagner KR, Ward LM, Weber DR for the DMD Care Considerations Working Group. Diagnosis and management of Duchenne muscular dystrophy, an update, part 1: Diagnosis, neuromuscular, rehabilitation, endocrine, and nutritional management. *Lancet Neuro*. 2018 Jan 23. PMID 29395989.

40. Birnkrant DJ, Bushby K, Bann CM, Alman BA, **Apkon SD**, Blackwell A, Case LE, Cripe L, Hadjiyannakis S, Olson AK, Sheehan DW, Bolen J, Weber DR, Ward LM for the DMD Care Considerations Working Group. Diagnosis and management of Duchenne muscular dystrophy, an update, part 2: respiratory, cardiac, bone health, and orthopaedic management. *Lancet Neuro*. 2018 Jan 23. PMID 29395990.

41. Birnkrant DJ, Bushby K, Bann CM, **Apkon SD**, Blackwell A, Colvin MK, Cripe L, Herron AR, Kennedy A, Kinnett K, Naprawa J, Nortiz G, Poysky J, Street N, Trout CJ, Weber DR, Ward LM for the DMD Care Considerations Working Group. Diagnosis and management of Duchenne muscular dystrophy, part 3: primary care, emergency management, psychosocial care, and transitions of care across the lifespan. *Lancet Neurology*. 2018 Feb 1. PMID 29398641.

42. **Apkon S**, Nortiz G. The primary care pediatrician: key to improving neuromotor outcomes. *Dev Med Child Neurol*. 2018 Sep;60(9):851. PMID: 30133721

43. **Apkon SD**, Alman B, Birnkrant DJ, Fitch R, Lark R, Mackenzie W, Weidner N, Sussman M. Orthopedic and Surgical Management of the Patient With Duchenne Muscular Dystrophy. *Pediatrics*. 2018 Oct;142(Suppl 2):S82-S89. PMID: 30275252

44. Case LE, **Apkon SD**, Eagle M, Gulyas A, Juel L, Matthews D, Newton RA, Posselt HF. Rehabilitation Management of the Patient With Duchenne Muscular Dystrophy. *Pediatrics*. 2018 Oct;142(Suppl 2):S17-S33. PMID: 30275246

45. Noritz G, Naprawa J, **Apkon SD**, Kinnett K, Racca F, Vroom E, Birnkrant DJ. Primary Care and Emergency Department Management of the Patient With Duchenne Muscular Dystrophy. *Pediatrics*. 2018 Oct;142 (Suppl 2):S90-S98. PMID 30275252.

46. Bouchard M, Vogel LF, **Apkon SD**. Restoration of Walking After Surgical Management of Equinus in a Non-ambulatory Child with Duchenne Muscular Dystrophy: A Case Presentation. *PMR*. 2019 March. PMID 30859710.

Book Chapters:

1. **Apkon SD**. Cerebral Palsy, *Pediatric Decision making* fourth edition. Berman S editor. Mosby, Philadelphia. 2003.

2. Wilson PE and **Apkon SD**. Examination of the Pediatric Patient. *Physical Medicine and Rehabilitation*, 3rd Edition, Braddom R. editor. Elsevier, 2005.

3. Wilson PE and **Apkon SD**. Examination of the Pediatric Patient. *Physical Medicine and Rehabilitation*, 3rd Edition, Braddom R. editor. Elsevier, 2007.

4. **Apkon SD** and Arnholz D. Medical Care of Children with Disabilities. *Pediatric Rehabilitation Principles and Practice*, Fourth Edition. Demos Medical Publishing, 2010.

5. **Apkon SD** and Rhodes, J. Cerebral Palsy, *Berman's Pediatric Decision Making* fifth edition. Bajaj L editor. Elsevier, India 2010.

6. **Apkon SD** and Rhodes J. Gait Abnormalities, *Berman's Pediatric Decision Making* fifth edition. Bajaj L editor. Elsevier, India 2010.

7. Wilson PE and **Apkon SD**. Examination of the Pediatric Patient. *Physical Medicine and Rehabilitation*, 3rd Edition, Braddom R. editor. Elsevier, 2010.

8. Pruitt D, McMahon M, Ried S, Apkon SD, Michaud L. Rehabilitation of the Child with Cancer. *Principles and Practice of Pediatric Oncology*. Pizzo P and Poplack D, editors. Lippincott, Williams & Wilkins. 2010.

9. **Apkon SD**. Osteoporosis. *Pediatrics: Rehabilitation Medicine Quick Reference*. Buschbacker RM editor. Demos Medical, 2011.

10. Osorio M and **Apkon S**. Ambulation Assistance. *Nelson Textbook of Pediatrics*, 20th Edition. Kliegman, Standton, St Geme, Schor editors. Elsevier. 2015.

11. **Apkon SD** and Myers E. Medical Care of Children with Disabilities. *Pediatric Rehabilitation Principles and Practice*, Fifth Edition. Demos Medical Publishing, 2015.

Other Publications:

1. **Apkon SD**. The Musculoskeletal System. *Families of Spinal Muscular Atrophy*. 2014.

Scientific Abstracts:

1. **Apkon S**, Drescher A, and Fenton L. Bone mineral density in children with myelomeningocele: a pilot study. *Dev Med Child Neurol*. 2002 Aug;91(44): 32.
2. Peragine J and **Apkon SD**. Acute arterial thrombosis in a child with Duchenne muscular dystrophy. *Arch Phys Med Rehabil*. 2002 Nov;83 (11): 1676.
3. Peragine J, Wilson PE, and **Apkon SD**. Juvenile dermatomyositis: A case report. *Arch Phys Med Rehabil*. 2002 Nov;83 (11): 1676.
4. Grzesiak J, Chang N, **Apkon SD**, and Wilson PE. The use of botulinum toxin type A in the treatment of children with congenital muscular torticollis. *Arch Phys Med Rehabil*. 2002 Nov;83 (11): 1642.
5. **Apkon S**. Use of Alendronate to treat osteoporosis in boys with muscular dystrophy: A report of 3 cases. *Arch Phys Med Rehabil*. 2003 Sep;84(9):E28.
6. Morton TM, **Apkon SD**, Wilson PE. Pneumatosis intestinalis as a complication in the rehabilitation setting: A report of 2 cases. *Arch Phys Med Rehabil*. 2003 Sep;84(9):E27.
7. Marcus DM, Kirkwood M, Wilson PE, **Apkon SD**. Cognitive impairments after cardiorespiratory arrest: A report of 3 cases. *Arch Phys Med Rehabil*. 2003 Sep;84(9):E27.
8. Wilson PE, **Apkon SD**, Clayton GH, Lich K, Matthews DJ. Evaluation of anoxic brain injuries in children using the coma/near coma scale. *Arch Phys Med Rehabil*. 2003 Sep;84(9):E27-E28.
9. **Apkon S** and Kirkwood M. Use of donepezil hydrochloride in a teenager with an anoxic brain injury: A case report. *Arch Phys Med Rehabil*. 2004 Sep;85(9):E44.
10. Bromley M, **Apkon S**, et al. Use of an inventive orthotic for severe neck muscle weakness: A case series. *Arch Phys Med Rehabil*. 2004 Sep;85(9):E47
11. Feldman A and **Apkon S**. Rehabilitation of Hemiparesis, Neglect, Mutism, and Dysphagia Following Hemispherectomy for the Treatment of Intractable Seizures: A Case Report. *Arch Phys Med Rehabil*. 2007 Sep;88(9): E78.
12. **Apkon S** and Graubert C. Patient Safety: Reducing Fractures in the Child who is Hospitalized. *Dev Med & Child Neuro*. 2012 Sep: 54: Sup 6.
13. Miller L, James KA, **Apkon SD**, Mathews K, Cunniff C, Lu Z, Holtzer C, Pandya S, and Cialfoni E. Risk Factors for Fractures among Males with Duchenne or Becker Muscular Dystrophy. American Academy of Physical Medicine & Rehabilitation Annual Assembly 2012.
14. Tsao E, Bjornson K, Christensen A, **Apkon S**. Outcomes of pediatric patients receiving inpatient rehabilitation care with cancer and non-cancer diagnoses. American Academy of Physical Medicine & Rehabilitation Annual Assembly 2013.
15. Fuentes M, Harmon R, Bjornson K, Christensen A, **Apkon S**. Functional outcomes among American Indian and Alaska Native children in inpatient pediatric rehabilitation. American Academy of Physical Medicine & Rehabilitation Annual Assembly 2013.

