

Bulletin No. 10

1st January 2026 – 31st March 2026

Highlighted abstracts:

2. **Caring at Home for Children with Medical Complexity: A study on Family Caregivers' Burden, Fatigue, and Musculoskeletal Pain**

10. **Parental Experiences of Receiving a Rare Genetic Disease Diagnosis for Their Child on Diagnosis Day**

20. **A Psychiatry Service for Parents of Children With Medical Complexity**

41. **Gaps and Challenges in the Transition of Care in Neuromuscular Disorders With a Focus on Duchenne Muscular Dystrophy**

49. **A Retrospective Review of the Travel Experiences of Children Using Home Mechanical Ventilation and Their Families**

52. **Moving from Challenge to Change: Redesigning Inpatient Care for Children with Complex Care Needs**

1. **Storytelling Intervention Relieved Pain During Tracheostomy Suction in Children Under Palliative Care: A Randomised Controlled Trial**

Akay, Gamze and Güdücü Tüfekci, Fatma (2026) *Scandinavian Journal of Caring Sciences* 40(1), pp. e70182

Pubmed: <https://pubmed.ncbi.nlm.nih.gov/41588469/>

2. **Caring at Home for Children with Medical Complexity: A study on Family Caregivers' Burden, Fatigue, and Musculoskeletal Pain**

Akyurek, Gokcen; Tekin, Vera and Gündoğmuş, Ezginur (2026) *Journal of Pediatric Nursing* 86, pp. 215–222

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41260049/>

3. Effect of nursing-led empowerment program on care burden and social isolation among caregivers having children with cerebral palsy: A quasi-experimental study

Ali, Halla Ali Abd El Hie; El-Ashry, Ayman Mohamed; Mohamed, Fatma Sayed Abdelaziz and others (2026) *Journal of Pediatric Nursing* 87, pp. 88–98

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41512595/>

4. Factors affecting the quality of life of caregivers of children with tracheostomy: an assessment tool

Alkhateeb, Ahmed; Alrusayyis, Danah; AlGhuneem, Aishah and others (2026) *Acta Otorhinolaryngologica Italica* :

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41817666/>

5. Continuous Ventilatory Support Without Hospitalization or Tracheotomies: A Retrospective Observational Study of Two Centers' Outcomes for Duchenne Muscular Dystrophy

Bach, John R.; Ishikawa, Yuka; Herrero, Maria Victoria and others (2026) *American Journal of Physical Medicine & Rehabilitation* 105(2), pp. 143–150

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40907980/>

6. Deaths among children with life-limiting or life-threatening conditions in Wales: a full population cohort

Bedendo, Andre; Jarvis, Stuart; Hain, Richard D. W. and others (2026) *Archives of Disease in Childhood* 111(3), pp. 260–263

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41167735/>

7. Impact of Home-Based Respiratory Physiotherapy in Nusinersen-Treated Patients with Spinal Muscular Atrophy

Be'er, Moria; Shperling, Lior; Rochman, Mika and others (2026) *Advances in Therapy* 43(4), pp. 1816–1826

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41770482/>

8. Family functioning and caring for a child with acquired brain injury: a systematic review and thematic analysis

Bos, Daniëlle P. A.; Hilberdink, Charlotte E.; Smeets, Kirsten C. and others (2026) *Journal of Pediatric Psychology* 51(2), pp. 107–133

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41671016/>

9. The sudden unexpected death in epilepsy grief study

Buchhalter, Jeffrey; Andrews, Catherine; Donalty, Jeanne and others (2026) *Epilepsy & Behavior : E&B* 177, pp. 110932

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41702217/>

10. Parental Experiences of Receiving a Rare Genetic Disease Diagnosis for Their Child on Diagnosis Day

Bullock, Isabel; Malone, Kristen Fishler and Turnwald, Abigail (2026) *American Journal of Medical Genetics. Part A* 200(1), pp. 67–76

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40820471/>

11. Pediatric Residents' Reflections on Communicating With Families of Children With Medical Complexity: A Qualitative Study

Butts, Breann; Huth, Kathleen; Herrmann, Lisa E. and others (2026) *Academic Pediatrics* 26(2), pp. 103191

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41338467/>

12. Unpacking the "black box" of safe respiratory physiotherapy interventions delivered in the home for children with cerebral palsy and medical complexity

Caird, B.; McGowan, N.; Depiazzi, J. and others (2026) *Physiotherapy* 130, pp. 101835

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41273942/>

13. Parents' Perceptions of Delays and Disabilities in Their Children Requiring Invasive Mechanical Ventilation

Calipo, Amanda; Green, Emma L.; Huang, Iris and others (2026) *Pediatric Pulmonology* 61(2), pp. e71481

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41660745/>

14. Assessing the impact of e-learning in caregiver training on paediatric epilepsy awareness and buccal Midazolam administration: A Scottish quality improvement study

Campbell, Jo; Asim, Fatima; McLardy, Hannah and others (2026) *Epilepsy & Behavior : E&B* 177, pp. 110942

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41707291/>

15. Time to genetic testing in Dravet syndrome: Trends, barriers, and opportunities for improvement

Carson, Ross A.; Maldonado Pacheco, John E.; Abath, Christina Briscoe and others (2026) *Epilepsia* 67(1), pp. 291–298

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41042141/>

16. The seen and unseen facets of Dravet syndrome across the disease trajectory: Insights from European ethnographic research

Dorris, Liam; Aras, Luis Miguel; Danse, Marion and others (2026) *Epilepsy & Behavior : E&B* 174, pp. 110809

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41317691/>

17. "We Learned by Hitting the Wall" Experiences of Parents With A Child With Hydrocephalus: A Qualitative Research

Düzgün, Mustafa Volkan; Temür, Büşra Nur and İşler, Ayşegül (2026) *Scandinavian Journal of Caring Sciences* 40(1), pp. e70213

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41796406/>

18. Longitudinal assessment of respiratory status utilising the amended Great Ormond Street Respiratory Score in treated spinal muscular atrophy type 1 children

Edel, Lisa; Stimpson, Georgia; Patelis, Vasileios and others (2026) *Neuromuscular Disorders : NMD* 61, pp. 106368

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41671781/>

19. Challenges associated with disclosing results from whole genome sequencing to diagnose paediatric rare diseases: analysis of parent-clinician interactions

Ellard, Holly; Ali, Jhumana; Buxton, Phoebe and others (2026) *Journal of Medical Genetics* 63(3), pp. 174–183

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41381188/>

20. A Psychiatry Service for Parents of Children With Medical Complexity

Esser, Kayla; Askari, Neda; Benny Gerard, Nichelle and others (2026) *Pediatrics* 157(3), pp. e2025070651. doi: 10.1542/peds.2025–070651

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41679340/>

21. A Telehealth-Based Transitional Care Model for Children with Medical Complexity

Fisk, Susan; Dominguez, Fidelity; Price, Kari and others (2026) *The American Journal of Nursing* 126(2), pp. 54–58

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41566602/>

22. Informing Dose for Pediatric Rare Diseases-A Survey of Recent Orphan Drugs Approvals

Fletcher, Elimika Pfuma; Kim, Chloe; Mei, Hannah and others (2026) *Clinical and Translational Science* 19(2), pp. e70503

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41707029/>

23. What Does Family-Centered Care Mean to You? A Qualitative Study Examining Perceptions of Mothers of Children With Medical Complexity

Fong, Vanessa C.; Baumbusch, Jennifer; Khan, Koushambhi and others (2026) *Journal of Family Nursing* 32(1), pp. 19–29

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41316806/>

24. Clinician Perceptions Around Management of Sleep Problems in Children With Neurodisability

Fullwood, Kasey; O'Donohue, Kate; Bernard, Anne and others (2026) *Child: Care, Health and Development* 52(2), pp. e70244

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41685683/>

25. The National Landscape of Hospitalizations for Children With Medical Complexity

Gabbay, Jonathan M.; Barnett, James R.; Bajaj, Benjamin V. M. and others (2026) *Hospital Pediatrics* 16(1), pp. e1–e7

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41412167/>

26. Mindfulness Apps to Improve Depression Severity and Family Management in Parents of Children With Medical Complexity: A Pilot Study

Gallegos, Cara; Toly, Valerie Boebel and Bailey, Matthew (2026) *Journal for Specialists in Pediatric Nursing : JSPN* 31(1), pp. e70011

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41319307/>

27. Beyond motor function: cognitive and language impairments in spinal muscular atrophy children treated with modern therapies

Guibert, Mathilde; Canton, Marie; Saunier, Delphine and others (2026) *Neuromuscular Disorders : NMD* 60, pp. 106340

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41616662/>

28. An Innovative Transitional Care Unit for Hospital to Home Transition of Children With Medical Complexity: A Qualitative Study of Parents' Experiences

Haspels, Heleen N.; Skomorowski, Nicole; Joosten, Koen F. M. and others (2026) *Child: Care, Health and Development* 52(2), pp. e70253

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41786468/>

29. Coping strategies of nurses caring for children with life-limiting and life-threatening conditions: An integrative review

Hurley, Fiona; Balanuta, Samantha and Flanagan, Paula (2026) *Journal of Pediatric Nursing* 86, pp. 549–558

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41406683/>

30. Communication behaviors of nurses and parent dyads of hospitalized home ventilator dependent children: A qualitative study

Johnson, Norah L.; Whitmore, Kim; Edwards, Cherise and others (2026) *Journal of Pediatric Nursing* 86, pp. 418–425

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41317647/>

31. Exploring Perceived Social Support in Family Caregivers of Children With Medical Complexity

Kennedy, Heather M.; DiFazio, Rachel L.; Crawford, Sybil and others (2026) *Journal of Pediatric Health Care : Official Publication of National Association of Pediatric Nurse Associates & Practitioners* 40(1), pp. 32–43

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41105068/>

32. Caregiver priorities and healthcare outcomes in a pediatric home care service for children with medical complexity: a quasi-experimental study

Kim, Kyua; Kim, Eunyoung; Seo, Hyunjin and others (2026) *European Journal of Pediatrics* 185(1), pp. 48–x

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41483102/>

33. Emergency department management of children with tracheostomies, feeding tubes, and cerebrospinal fluid shunts

Kling, David Jr; Jeong, Yae Sul; Trevino, Robert and others (2026) *Pediatric Emergency Medicine Practice* 23(3), pp. 1–28

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41740155/>

34. Barriers and enablers to community living: A mixed-methods systems study of young adults with life-limiting conditions

Lakhani, Ali; Senyel, Deniz; Mackenzie-Stewart, Ruth and others (2026) *Palliative Medicine* 40(4), pp. 565–573

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41724576/>

35. "Not Only Has She Survived, But She Lives a Happy Life": Parents' Perspectives and Experiences of a Novel Disease-Modifying Therapy for Spinal Muscular Atrophy in Sweden

Landfeldt, Erik; Udo, Camilla; Cortina-Borja, Mario and others (2026) *Journal of Child Neurology* 41(2), pp. 156–162

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40625177/>

36. Tasks for Assessing Dystonia in Young People With Cerebral Palsy

Lott, Emma; Rust, Alyssa; Dure, Leon and others (2026) *Pediatric Neurology* 174, pp. 126–134

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41223735/>

- 37. Clinical characteristics and gaps in palliative care among tracheostomized children: a retrospective observational study**
Luna, Luziane Lais Sabino Silva; Duarte, Maria do Carmo Menezes Bezerra; Levy, Sheyla Suelle Dos Santos and others (2026) *Jornal De Pediatria* 102(1), pp. 101480
PubMed: <https://pubmed.ncbi.nlm.nih.gov/41320165/>
- 38. Sudden unexpected death in epilepsy (SUDEP): Risk management of pediatric patients with epilepsy**
Lutz, Laura; Becker, Lena Luise; Koch, Alwina and others (2026) *Epilepsia Open* 11(2), pp. 422–434
PubMed: <https://pubmed.ncbi.nlm.nih.gov/41557206/>
- 39. Identifying the knowledge needs and preferences of parents of children with rare diseases regarding clinical trials: a scoping review protocol**
Mabbott, Annie P.; Knisley, Lisa and Scott, Shannon D. (2026) *Systematic Reviews* 15(1), pp. 74. doi: 10.1186/s13643-0).
PubMed: <https://pubmed.ncbi.nlm.nih.gov/41645315/>
- 40. The health and well-being of children with medical complexity and their parents' when admitted to inpatient care units: A scoping review**
Mackay, Lyndsay; Dewan, Tammie; Asaad, Lauren and others (2026) *Journal of Child Health Care : For Professionals Working with Children in the Hospital and Community* 30(1), pp. 188–210
PubMed: <https://pubmed.ncbi.nlm.nih.gov/39881559/>
- 41. Gaps and Challenges in the Transition of Care in Neuromuscular Disorders With a Focus on Duchenne Muscular Dystrophy**
Marcassoli, Alessia; Rajapakse, Nethmi; Guastafierro, Erika and others (2026) *Pediatric Neurology* 174, pp. 74–80
PubMed: <https://pubmed.ncbi.nlm.nih.gov/41192310/>
- 42. Multiprofessional Clinician Perspectives on Communicating About Brain Death in Children**
Martz, Katherine; Mirpuri, Karan K.; Malone, Sara and others (2026) *Journal of Pain and Symptom Management* 71(5), pp. 618–629.e3
PubMed: <https://pubmed.ncbi.nlm.nih.gov/41587626/>
- 43. Frequency and nature of sleep disturbances amongst children with cerebral palsy in Northern Ireland: A cross-sectional study**

McCavert, Mary-Elaine; Perra, Oliver; McConnell, Karen and others (2026) *Research in Developmental Disabilities* 170, pp. 105255

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41702278/>

44. Bereavement Experiences Among Parents of Children With Spinal Muscular Atrophy Type 1

Mulé, Christina M.; Riley, Abigail; Lerner, Debra and others (2026) *Journal of Pain and Symptom Management* 71(1), pp. 89–98.e3

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40992641/>

45. Connect, pause and reflect: Multidisciplinary clinicians' shared challenges and sustaining strategies caring for children with severe neurological impairment

Nevin, Suzanne M.; Le Marne, Fleur A.; Kelada, Lauren and others (2026) *European Journal of Paediatric Neurology : EJPN : Official Journal of the European Paediatric Neurology Society* 60, pp. 15–23

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41232234/>

46. Family and Caregiver Quality of Life in Pediatric Neuromuscular Diseases: Psychosocial and Disease-related Predictors

Ortega, Javiera; Vázquez, Natalia; García-Sanchoyerto, Maddalen and others (2026) *Journal of Developmental and Behavioral Pediatrics : JDBP* 47(1), pp. e59–e65

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40960360/>

47. Is Health Literacy Associated With Parental Comprehension of Discharge Medications for Children With Medical Complexity?

Oseni, Laretta A.; Sadaf, Salma; Devaraj, Apurva and others (2026) *Hospital Pediatrics* 16(2), pp. e92–e99

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41539478/>

48. EPIC-ND: a multi-site, randomised controlled trial evaluating the effectiveness of social prescribing for the unmet social needs of children with a neurodisability and their parent/carers - a study protocol

Ostojic, Katarina; Chiu, Serena; Takchi, Sandra and others (2026) *BMJ Paediatrics Open* 10(1), pp. e003847. doi: 10.1136/bmjpo-003847

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41633762/>

49. A Retrospective Review of the Travel Experiences of Children Using Home Mechanical Ventilation and Their Families

Oyarzun, Ignacio; Cithiravel, Nisha; Kuyntjes, Sarah and others (2026) *Pediatric Pulmonology* 61(3), pp. e71565

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41823356/>

50. Judicial access to medicines for rare diseases: characteristics of lawsuits against the Federal Government

Pepe, Vera Lúcia Edais; Baptista, Michelly Ribeiro; Ventura, Miriam and others (2026) *Ciencia & Saude Coletiva* 31(1), pp. e14312025

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41615126/>

51. Attitudes of health and social care professionals towards the use of blended diets for enteral tube feeding for children and young people

Phillips, Gemma; McCullough, Fiona and Hemingway, Pippa (2026) *Journal of Child Health Care : For Professionals Working with Children in the Hospital and Community* 30(1), pp. 7–22

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39559987/>

52. Moving from Challenge to Change: Redesigning Inpatient Care for Children with Complex Care Needs

Popejoy, Emma; Coad, Jane; Cohen, Eyal and others (2026) *Children* 13(4)

<https://www.mdpi.com/2227-9067/13/4/502>

53. A scoping review of the clinical outcomes and use of blenderized tube feeds and commercial food-based formulas in pediatrics

Ramuscak, Alyssa V.; Martincevic, Inez and Hulst, Jessie M. (2026) *Clinical Nutrition ESPEN* 71, pp. 102845

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41390062/>

54. Spirituality in children with life-limiting, life-threatening and/or complex chronic conditions: A scoping review

Santos Ferreira, Mónica; Pereira, Diana Gomes and Caldeira, Sílvia (2026) *Journal of Pediatric Nursing* 86, pp. 526–534

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41380308/>

55. Services and supports for child-welfare involved children with medical complexity: Data from a national survey of child welfare agencies

Seltzer, Rebecca R.; Chung, Joyce; Cruce, Amanda and others (2026) *Child Abuse & Neglect* 174, pp. 107948

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41713179/>

56. Mortality and cause of death in childhood onset epilepsy: A population-based cohort study in Finland

Starck, Christian; Helminen, Mika; Nevalainen, Olli Po and others (2026) *Seizure* 137, pp. 138–142

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41833258/>

57. Overgranulation of stoma sites in children with an enteral feeding tube: an evidence-based treatment pathway

Tatterton, Michael; Mulcahy, Jane; Willcox, Nicky and others (2026) *Nursing Children and Young People* 38(1), pp. 12–18

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40717544/>

58. SUDEP Awareness and Effect on Parental Trauma, Grief, and Coping After the Death of a Child: A Qualitative Investigation

Tokatly Latzer, Itay; Friedman, Daniel; Williams, David N. and others (2026) *Neurology* 106(5), pp. e214623

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41616227/>

59. Complications and factors associated with emergency department presentation for pediatric tracheostomy patients

Trope, Michal; Tabangin, Meredith; Hart, Catherine K. and others (2026) *International Journal of Pediatric Otorhinolaryngology* 203, pp. 112776

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41785817/>

60. Sleep in children with spinal muscular atrophy and their caregivers: Exploring sleep problems and the need for care

van Rijssen, Ilse Margot; Rodenburg, Sanne; Alsem, Mattijs and others (2026) *Research in Developmental Disabilities* 169, pp. 105238

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41616598/>

61. Ultra-refractory epilepsy: The newly described entity

Vinklársek, Jan; Bůřilová, Petra; Raouf Zadeh, Mojdeh and others (2026) *Epilepsia Open* 11(1), pp. 220–229

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41363200/>

62. Treatment evolution in spinal muscular atrophy: insights from the SMARtCARE registry

Voigt-Müller, Cornelia; Pfaffenlehner, Michelle; Bernert, Günther and others (2026) *Brain : A Journal of Neurology* 149(3), pp. 818–827

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41431300/>

63. Medical Device Design Flaws for Children With Medical Complexity at Home

Walsh, Peter; Seewald, Sofia; Castillo, Leo and others (2026) *Pediatrics* 157(3), pp. e2025073091. doi: 10.1542/peds.2025-073091

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41663056/>

64. Practices and outcomes of multidisciplinary collaboration to support the integration of healthcare into the daily lives of technology-dependent children

Watanabe, Rie and Shigematu, Yukako (2026) *Japan Journal of Nursing Science : JJNS* 23(1), pp. e70035

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41354558/>

65. Nurses' Experiences of Caring for Children on Long-Term Mechanical Ventilation

Winblad von Walter, Annika; Lundberg, Veronica; Sonnemo, Sara and others (2026) *Nursing in Critical Care* 31(1), pp. e70330

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41536128/>

66. Sense of competency and caregiver burden among parents of children with medical complexity: A cross-sectional study

Yamaguchi, Miku; Yamada, Masako; Shirasaka, Maki and others (2026) *Journal of Pediatric Nursing* 86, pp. 35-43

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