

Bulletin No. 9

1st September 2025 – 31st December 2025

Highlighted abstracts:

- 4. YouTube as a Source of Patient Education in Medulloblastoma: How Reliable is it?
- 15. "My child is completely underestimated": Canadian parents' perspectives on implementing an accessible language comprehension assessment for non-speaking children with cerebral palsy
- 21. Posterior drooling and saliva aspiration in children with cerebral palsy: hidden threats
- 23. Understanding what matters to young people with life-limiting and life-threatening conditions: a qualitative study to inform the development of a young person end-of-life capability measure
- 28. "I don't grieve as much as I used to": A qualitative study on parents of children with rare and undiagnosed conditions navigating grief in the context of uncertainty
- 46. "Just realising that I wasn't alone... was profound": a mixed-methods evaluation of a pilot peer-to-peer wellbeing program for carers of children with rare epilepsies

1. 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/>

2. 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/>

- 3. 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/>
- 4. YouTube as a Source of Patient Education in Medulloblastoma: How Reliable is it?**
Abat, Eray and Durmus, Nimetullah Alper (2025) *World Neurosurgery* 204, pp. 124527
PubMed: <https://pubmed.ncbi.nlm.nih.gov/41067690/>
- 5. Health outcomes of children with Prader-Willi or Angelman syndromes: a European population-based multicentre study**
Abate, Maria Valentina; Barisic, Ingeborg; Santoro, Michele and others (2025) *Archives of Disease in Childhood* 110(11), pp. 899–904
PubMed: <https://pubmed.ncbi.nlm.nih.gov/40484454/>
- 6. Status Dystonicus in Children: Is it more Common than we Realize?**
Al Azri, Nadia; Vogt, Lindsey M.; LeBlanc-Millar, Andrea and others (2025) *Movement Disorders Clinical Practice* 12(10), pp. 1629–1634
PubMed: <https://pubmed.ncbi.nlm.nih.gov/40384399/>
- 7. Care of Infants and Children with Tracheostomies: An Official American Thoracic Society Clinical Practice Guideline**
Amin, Reshma; Agarwal, Amit; Chiang, Jackie and others (2025) *American Journal of Respiratory and Critical Care Medicine* 211(11), pp. 2001–2020
PubMed: <https://pubmed.ncbi.nlm.nih.gov/41123183/>
- 8. 'For the love of God, just refer me': a co-produced qualitative study of the experiences of people with Tourette Syndrome and tic disorders accessing healthcare services in the UK**
Babbage, Camilla May; Davies, E. Bethan; Jones, Daniel P. and others (2025) *BMJ Open* 15(9), pp. e098306–098306
PubMed: <https://pubmed.ncbi.nlm.nih.gov/40912712/>
- 9. Innovative treatments of pediatric spinal muscular atrophy: The decision-making process in France**
Biotteau, Maelle; Ropars, Juliette; Chabrol, Brigitte and others (2025) *European Journal of Medical Genetics* 78, pp. 105044
PubMed: <https://pubmed.ncbi.nlm.nih.gov/40935015/>
- 10. The Family Stress Model in families of children with rare diseases: a cross-sectional multilevel path analysis for understanding family dynamics**

Boettcher, Johannes; Hohmann, Sarah; Daubmann, Anne and others (2025) *Frontiers in Public Health* 13, pp. 1713613

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41341441/>

11. Angelman Syndrome: Multidisciplinary Management

Bridges, Whitney A.; Temples, Heide S. and Lowe, Tracy B. (2025) *Journal of Pediatric Health Care : Official Publication of National Association of Pediatric Nurse Associates & Practitioners* 39(6), pp. 968–975

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40643417/>

12. Creation of a Novel Longitudinal Pediatrics Resident Curricular Program Addressing the Medical and Social Needs of Children with Medical Complexity

Bruton, Lucas; Spewak, Michael; Grage, Jennifer and others (2025) *The Journal of Pediatrics* 287, pp. 114751

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40712741/>

13. The Impact of Coronavirus Disease of 2019 Pandemic on Home Health Nursing Availability in Pediatric Patients After Tracheostomy Placement

Cacho, Ferdinand; Carr, Katherine A.; Bedoya, Mariana and others (2025) *Pediatric Pulmonology* 60(9), pp. e71273

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40911396/>

14. Parent perceptions of their child's cognitive impairment linked to their views on support for healthcare transition

Clark, Sarah J.; Cowan, Anne E.; Raja, Sahana and others (2025) *Epilepsia Open* 10(5), pp. 1719–1725

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40847800/>

15. "My child is completely underestimated": Canadian parents' perspectives on implementing an accessible language comprehension assessment for non-speaking children with cerebral palsy

Coan-Brill, Juno; Friesen, Jodi; Kay, Jessica and others (2025) *Disability and Rehabilitation* 47(20), pp. 5214–5226

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40018756/>

16. Acceptability and feasibility of a novel postural management night-time intervention to improve respiratory health of children and young people with complex neurodisability (Breathe-Easy): proof of concept study

Crombie, Sarah; Sellers, Diane; Kapur, Akshat and others (2025) *Physiotherapy* 129, pp. 101816

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40913932/>

17. Bereaved parents' perspectives of factors influencing decision-making about place of end-of-life care for children with life-limiting, life-threatening conditions: an all-Ireland qualitative study

Crowe, Ashleen; McCauley, Rachel; Corcoran, Yvonne and others (2025) *BMC Palliative Care* 24(1), pp. 294–z

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41286836/>

18. Social Media Use Among Parents and Caregivers of Children With Rare Genetic Diseases: Scoping Review

Davis, Charlotte; Bogaert, Laura; Powell, John and others (2025) *Journal of Medical Internet Research* 27, pp. e77087

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41313807/>

19. Dravet syndrome: Insights into seizure and speech progression from registry data

Delporte, Margaux; Verbeeck, Johan; Brambilla, Isabella and others (2025) *Epilepsy & Behavior : E&B* 170, pp. 110459

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40382994/>

20. Posttraumatic Stress in Parents of Hospitalized Children With Medical Complexity

Dewan, Tammie; Whiteley, Andrea; Birnie, Kathryn and others (2025) *Hospital Pediatrics* 15(11), pp. 921–931

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41038625/>

21. Posterior drooling and saliva aspiration in children with cerebral palsy: hidden threats

Dias, Bruno Leonardo Scofano and de Lima, Fernanda Marinho (2025) *World Journal of Pediatrics : WJP* 21(12), pp. 1230–1243

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41191295/>

22. Respiratory management in spinal muscular atrophy: development of a global outcome measure

Edel, L.; Civitello, M.; Muntoni, F. and others (2025) *Neuromuscular Disorders : NMD* 56-57, pp. 106253

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41218385/>

23. Understanding what matters to young people with life-limiting and life-threatening conditions: a qualitative study to inform the development of a young person end-of-life capability measure

Floredin, Isabella; Husbands, Samantha; Neilson, Susan and others (2025) *Social Science & Medicine* (1982) 383, pp. 118335

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40763405/>

24. Nasogastric tube feeding under physical restraint: understanding the effects on parents and how to support them

Fuller, Sarah; Thomson, Sharon; Nicholls, Dasha and others (2025) *Nursing Children and Young People* 37(5), pp. 14–20

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39829345/>

25. Behavioural sleep interventions for the management of non-respiratory sleep disorders in children with neurodisability

Fullwood, Kasey; Thorpe, Karen; Coles, Laetitia and others (2025) *Sleep Medicine Reviews* 84, pp. 102185

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41202522/>

26. Evaluating health related quality of life in paediatric and adult patients who utilise home enteral tube feeding

Hinchcliff, Mercedes; Clancy, Annabel; Crawford, Courtney and others (2025) *Clinical Nutrition (Edinburgh, Scotland)* 52, pp. 189–194

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40780130/>

27. The role of assistive devices and technologies in the activities and participation in everyday life of children with cerebral palsy - a scoping review

Hoekstra, Dyon and Thiele, Annett (2025) *Disability and Rehabilitation Assistive Technology* 20(7), pp. 1994–2015

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40928660/>

28. "I don't grieve as much as I used to": A qualitative study on parents of children with rare and undiagnosed conditions navigating grief in the context of uncertainty

Hoffmann, Tara Maria; Friedrich, Bettina and Lewis, Celine (2025) *Journal of Genetic Counseling* 34(6), pp. e70149

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41317142/>

29. Evaluating the impact of school-based rebound therapy on chest health in children and young people with neurodisability and respiratory issues: a series of single case studies

Knight Lozano, Rachel; Shannon, Harriet; Bell, Kayleigh and others (2025) *Disability and Rehabilitation* 47(24), pp. 6384–6395

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40119636/>

30. Ketogenic Diet in Niemann-Pick Type C: Insights From a Case Report

Kulu, Bahar; Kisa, Pelin Teke; Er, Esra and others (2025) *International Journal of Developmental Neuroscience : The Official Journal of the International Society for Developmental Neuroscience* 85(6), pp. e70052

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40898442/>

31. Insights into the lives of families of children with neurodisabilities who have sleep problems

Langdon, Grace; O'Neil, Matilda; Cooke, Emma and others (2025) *Sleep Health* 11(6), pp. 770–780

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41047332/>

32. 'They don't know what to do with our children': Experiences and views on feeding and swallowing from parents of children who use long-term ventilation

Lee, Sabrena; Marshall, Jeanne; Clarke, Michael and others (2025) *Journal of Child Health Care : For Professionals Working with Children in the Hospital and Community* 29(4), pp. 842–860

PubMed: <https://pubmed.ncbi.nlm.nih.gov/38590229/>

33. Baclofen and Botulinum Toxin A Use in Tone Management for Children With Cerebral Palsy: A Review of Current Literature and Research Gaps in Pre- and Perioperative Care

Li, Michael; Rozen, Naama; Wortley, Kate and others (2025) *Pediatric Neurology* 172, pp. 28–34

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40882243/>

34. Losing a child due to a life-limiting diagnosis-parental well-being and quality of life: nationwide survey

Lykke, Camilla; Sjøgren, Per and Ekholm, Ola (2025) *BMJ Supportive & Palliative Care* 15(6), pp. 796–804

PubMed: <https://pubmed.ncbi.nlm.nih.gov/34969696/>

35. Oral health in children with rare diseases and gastrostomy tubes: A retrospective database cohort study

Magnéli, Anna Nielsen; Sabel, Nina; Krekmanova, Larisa and others (2025) *Nutrition in Clinical Practice : Official Publication of the American Society for Parenteral and Enteral Nutrition* 40(5), pp. 1158–1165

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40762370/>

36. The Mental and Behavioral Health Services Available to Children With Medical Complexity in Complex Care Programs

Malik, Kristina E.; Shelton, Charlene; Marin, Amber and others (2025) *Clinical Pediatrics* 64(12), pp. 1717–1725

PubMed:

37. Experiences of growth among nurses caring for children with life-limiting conditions: insights from a narrative review

Massaad, Micha and Friedel, Marie (2025) *BMJ Paediatrics Open* 9(1), pp. e004082. doi: 10.1136/bmjpo-004082

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41274665/>

38. Parental Stress and Family Quality of Life in Families of Individuals Living With Angelman Syndrome

Merton, Catherine; Gwaltney, Angela; Booman, Anna and others (2025) *Journal of Intellectual Disability Research : JIDR* 69(9), pp. 822–839

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40891560/>

39. Quality of life outcomes and predictors for youth with intellectual disability and rare diseases

Morán, M. Lucía; Monsalve, Asunción; Fontanil, Yolanda and others (2025) *Research in Developmental Disabilities* 164, pp. 105071

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40540825/>

40. Rehabilitation practices for childhood spinal muscular atrophy

Mortenson, Patricia; Cielecka, Julia; Harrison, Emma and others (2025) *Disability and Rehabilitation* 47(21), pp. 5538–5547

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40163566/>

41. Too vulnerable? Successful practices for conducting research with children and young people who have life-limiting or life-threatening illness

Namisango, Eve; Friedel, Marie; Yurduşen, Sema and others (2025) *Palliative Medicine* 39(9), pp. 1021–1029

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40913482/>

42. "Nobody listened to us for years": Parents' experiences of provider communication in the diagnostic odyssey

Nguyen, Michelle M.; Mahfoozi, Sevil; Bonner, Devon and others (2025) *Molecular Genetics and Metabolism* 146(4), pp. 109283

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41232198/>

43. Glycopyrrolate for Drooling in Children With Neurodisability: Multicenter Study

Ozbudak, Pinar; Ucar, Habibe Koc; Orgun, Leman Tekin and others (2025) *Journal of Child Neurology* 40(8), pp. 634–640

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40232683/>

44. Family Caregivers' Experiences of Services for Children With Medical Complexity: A Systematic Review and Qualitative Evidence Synthesis

Page, Bethan; Holder, Pru; Doidge, Katie and others (2025) *Health Expectations : An International Journal of Public Participation in Health Care and Health Policy* 28(5), pp. e70452

PubMed:

45. Care strategies for children with tracheostomy at school: a scoping review

Pessanha, Fernanda Borges; Depianti, Jéssica Renata Bastos; Pimentel, Thaís Guilherme Pereira Pinheiro and others (2025) *Revista Da Escola De Enfermagem Da U S P* 59, pp. e20250096–0096en. eCollection 2025

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41024504/>

46. "Just realising that I wasn't alone... was profound": a mixed-methods evaluation of a pilot peer-to-peer wellbeing program for carers of children with rare epilepsies

Pierce, Kristine; Murphy, Jack Bernard; Robertson, Eden G. and others (2025) *Orphanet Journal of Rare Diseases* 20(1), pp. 524–0

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41121411/>

47. Ethical challenges and justice concerns for infants and children with life-limiting conditions and significant disability, including trisomy 13 and 18

Pyle, Alaina K. and Mercurio, Mark R. (2025) *Seminars in Perinatology* 49(6), pp. 152101

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40517086/>

48. Mechanical ventilation for young people with Duchenne muscular dystrophy: a factorial survey of the main influences on clinician decision-making

Quirke, M. B.; Hill, K.; Alexander, D. and others (2025) *European Journal of Pediatrics* 184(11), pp. 706–2

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41114800/>

49. Systematic review of paediatric SUDEP and epilepsy-related deaths to inform a safety counselling checklist for clinical practice

Rattihalli, Rohini Ranganath; Ashby, Sammy; Burrows, Lisa and others (2025) *Seizure* 131, pp. 172–179

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40614301/>

50. Memory-making interventions for children with life-threatening or life-limiting conditions and their families: A systematic review of evidence and implications for practice

Safarifar, Razieh; Kiernan, Gemma; Corcoran, Yvonne and others (2025) *Palliative Medicine* 39(8), pp. 871–883

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40709803/>

51. Efficacy and safety of levetiracetam versus phenobarbitone for neonatal seizures: A systemic review and meta-analysis

Salim, Najwa; Qadri, Syeda Iqra; Chughtai, Muhammad Aswab Iqbal and others (2025) *Clinical Neurology and Neurosurgery* 258, pp. 109155

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40975024/>

52. Efficacy and safety of cannabidiol in children with developmental and epileptic encephalopathies: A systematic review

Saranti, Anna; Dragoumi, Pinelopi; Pavlogiannis, Konstantinos and others (2025) *Seizure* 133, pp. 114–127

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41135306/>

53. Non-seizure symptoms and broader seizure impacts in patients with Dravet syndrome and Lennox-Gastaut syndrome in clinical practice settings: Results from a multinational survey

Shah, Drishti; Villanueva, Vicente; Dlugos, Dennis and others (2025) *Epilepsia Open* 10(6), pp. 1783–1797

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40982357/>

54. Gastrointestinal symptoms are common in patients with new-onset refractory status epilepticus (NORSE)

Shrestha, Anima; Silveira, Lori J.; Thomas, Divya and others (2025) *Neurological Sciences : Official Journal of the Italian Neurological Society and of the Italian Society of Clinical Neurophysiology* 46(10), pp. 5305–5314

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40835780/>

55. Transforming Pediatric Rare Disease Drug Development: Enhancing Clinical Trials and Regulatory Evidence With Virtual Patients

Sips, Fianne; Virgolin, Marco; Pasculli, Giuseppe and others (2025) *CPT: Pharmacometrics & Systems Pharmacology* 14(11), pp. 1739–1742

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40757668/>

56. Somewhere to go: a position paper on addressing gaps in transition care for adults with childhood-onset rare diseases

Tosi, Laura L.; Hart, Tracy S.; Beug, Gabriela and others (2025) *Orphanet Journal of Rare Diseases* 20(1), pp. 498–0

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41039450/>

57. Predictors of life satisfaction in fathers of children with cerebral palsy

Turhan, Atahan; Aslan, Menşure and Karaçay, Başak Çiğdem (2025) *Revista Paulista De Pediatria : Orgao Oficial Da Sociedade De Pediatria De Sao Paulo* 43, pp. e2025001–

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41259571/>

58. Employing a multidisciplinary tracheostomy team to improve the care process of pediatric patients

Vankayalapati, Amulya; Coleman, Michelle; Germann, Janet N. and others (2025) *International Journal of Pediatric Otorhinolaryngology* 198, pp. 112557

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40945495/>

59. Caregiver Perspectives on Racism and Bias in Navigating the Care of Children with Long-Term Ventilation via Tracheostomy

Võ, Holly Hòa; Patel, Kareena; Snyder, Cyndy and others (2025) *The Journal of Pediatrics* 287, pp. 114765

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40780671/>

60. Transitions From Pediatric to Adult Neuromuscular Care: A Practical Guide

Wozow, Cynthia and Mosher, Kathryn (2025) *Muscle & Nerve* 72(4), pp. 558–565

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40727999/>

61. Capability wellbeing of parents caring for children with rare diseases: a national cross-sectional study

Yu, Jiazhou; Zhang, Huanyu; Chen, Shanquan and others (2025) *BMC Public Health* 25(1), pp. 4190–8

PubMed: <https://pubmed.ncbi.nlm.nih.gov/41316073/>

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