NINDS CDE Presentations

PRESENTATIONS IN 2020

   **Authors:** Katelyn Gay, BS; Nicholas Barbaro, MD; Jacqueline French, MD; William D. Gaillard, MD; Damon Collie, MSHS; Muniza Sheikh, MS, MBA; M. Carolina Mendoza-Puccini, MD; Vicky Whittemore, PhD on behalf of the Epilepsy CDE Oversight Committee and Working Groups.

   **Authors:** Joline Brandenburg, MD, Sarah McIntyre, PhD, Robin Feldman, BS, MBA, Ilar Edun, BA, Joy Esterlitz, MS, and M. Carolina Mendoza-Puccini, MD, on behalf of the NINDS/AACPDM Cerebral Palsy CDE Oversight Committee and Working Group.

   **Authors:** Theresa Sukal Moulton, DPT, PhD, M. Carolina Mendoza-Puccini, MD and Robin Feldman, BS, MBA, on behalf of the NINDS/AACPDM Cerebral Palsy CDE Oversight Committee and Working Groups.

   **Authors:** Robin Feldman, BS, MBA; Ian Spector, BS, MPS; Muniza Sheikh, MS, MBA; Joy Esterlitz, MS; Lyn B. Jakeman, PhD; M. Carolina Mendoza-Puccini, MD; Vanessa Noonan, PhD, PT on behalf of the NINDS Spinal Cord Injury CDE Oversight Committee.

   **Authors:** Muniza Sheikh, MS, MBA; Damon Collie, MSHS; Ilar Edun, BA; Robin Feldman, MBA; Andrew Franklin, BA; Katelyn Gay, BS; Rebecca Johnson, PhD; Ian Spector, MPS; Joy Esterlitz, MS; M. Carolina Mendoza-Puccini, MD. Virtual poster presentation.

NINDS CDE Presentations

Authors: Robin Feldman, BS, MBA; Muniza Sheikh, MS, MBA; Ilar Edun, BA; Joy Esterlitz, MS; Joline Brandenburg, MD; Sarah McIntyre, PhD; M. Carolina Mendoza-Puccini, MD; on behalf of the NINDS Cerebral Palsy CDE Oversight Committee.

7. April 2020: – American Academy of Neurology 72nd Annual Virtual Meeting, 2020. National Institute of Neurological Disorders and Stroke Epilepsy Common Data Element Updates: Seizure Severity Instruments, Diagnostic Tools, and MRI Recommendations. Virtual poster presentation. Authors: Katelyn Gay, BS; Joan Austin, PhD, RN, FAAN; Jacqueline French, MD; William D. Gaillard, MD; Ruth Shinnar, RN, MSN; Nicholas Barbaro, MD; Daniel Lowenstein, MD; Muniza Sheikh, MS, MBA; Damon Collie, MSHS; Joy Esterlitz, MS; Vicky Whittemore, PhD; M. Carolina Mendoza-Puccini, MD on behalf of the Epilepsy CDE Oversight Committee and Imaging Working Group.

8. April 2020: – American Academy of Neurology 72nd Annual Virtual Meeting, 2020. National Institute of Neurological Disorders and Stroke (NINDS) Common Data Elements (CDEs): Updates to the Stroke V1.0 Recommendations. Virtual poster presentation. Authors: Damon Collie MSHS; Katelyn Gay, BS; Muniza Sheikh, MS, MBA; Joy Esterlitz, MS; Jeffrey L. Saver, MD, FAHA, FAAN; Steven Warach, MD, PhD; Clinton B. Wright, MD, MS, FAAN; M. Carolina Mendoza-Puccini, MD; Scott Janis, PhD on behalf of the Stroke V2.0 CDE Working Group.

9. February 2020: – AHA /ASA International Stroke Conference February 19 – February 21, 2020, Los Angeles, CA. National Institute of Neurological Disorders and Stroke Common Data Elements: Public Review and Updates to the Stroke Recommendations. Poster presentation. Authors: Katelyn Gay, BS; Damon Collie, MSHS; Muniza Sheikh, MS, MBA; Joy Esterlitz, MS; Jeffrey Saver, MD, FAHA, FAAN; Steven Warach, MD, PhD; Clinton B. Wright, MD, MS, FAAN; M. Carolina Mendoza-Puccini, MD; Scott Janis, PhD on behalf of the Stroke V2.0 CDE Working Group.

PRESENTATIONS IN 2019

10. December 2019: – 73rd American Epilepsy Society Annual Meeting December 6 – December 10, 2019, Baltimore, MD. The National Institute of Neurological Disorders and Stroke Epilepsy Common Data Element Updates: Seizure Severity and Diagnostic Recommendations. Poster presentation. Authors: Katelyn Gay, BS; Joan Austin, PhD, RN, FAAN; Jacqueline French, MD; Dale Hesdorffer, PhD; Ruth Shinnar, RN, MSN; Nicholas Barbaro, MD; Daniel Lowenstein, MD; Muniza Sheikh, MS, MBA; Damon Collie, MSHS; Joy Esterlitz, MS; Vicky Whittemore, PhD; M. Carolina Mendoza-Puccini, MD on behalf of the Epilepsy CDE Oversight Committee.

11. November 2019 – International Spinal Cord Society 58th Annual Scientific Meeting, November 5 – November 7, 2019, Nice, France. Updates to the National Institute of Neurological Disorders and Stroke (NINDS) Spinal Cord Injury (SCI) Common Data Element Recommendations. Poster presentation. Authors: Robin Feldman, BS, MBA; Kristen Joseph MA; Muniza Sheikh, MS, MBA; Joy Esterlitz, MS; Vanessa Noonan, PhD, PT; Lyn B. Jakeman, PhD; M. Carolina Mendoza-Puccini,
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MD; on behalf of the NINDS Spinal Cord Injury CDE Oversight Committee.

12. September 2019 – American Academy for Cerebral Palsy and Developmental Medicine 73rd Annual Meeting/IAACD 2nd Triannual Meeting, September 17 – September 21, 2019, Anaheim, CA. The Influence of ICF and ICF Core Sets in Selecting the NINDS Cerebral Palsy Common Data Element Outcome Measures. Poster presentation. Authors: Joline Brandenburg, MD; Verónica Schiariti, MD, PhD; M. Carolina Mendoza-Puccini, MD; Robin Feldman, BS, MBA; Kristen Joseph, MA; and Joy Esterlitz, MS on behalf of the Cerebral Palsy CDE Oversight Committee and Working Group.

13. September 2019 – American Academy for Cerebral Palsy and Developmental Medicine 73rd Annual Meeting/IAACD 2nd Triannual Meeting, September 17 – September 21, 2019, Anaheim, CA. NINDS Cerebral Palsy Common Data Elements: Updates; Relationship to the International Classification of Functioning, Disability, and Health (ICF); Applications for International Research; and Clinical Utility. Instructional Course. Authors: Joline Brandenburg, MD Verónica Schiariti, MD, PhD Carolina Mendoza-Puccini, MD, Robin Feldman, BS, MBA, Sarah McIntyre, PhD on behalf of the NINDS/AACPDM Cerebral Palsy CDE Oversight Committee and Working Groups.


15. May 2019 – American Academy of Neurology 71st Annual Meeting, May 4 – May 10, 2019, Philadelphia, PA. Friedreich’s ataxia Common Data Element Review: Updates to the National Institute of Neurological Disorders and Stroke Friedreich’s ataxia (FA) Common Data Element Recommendations: 2018 FA Working Group Review. Poster presentation. Authors: Ilar Edun, BA; Katelyn Gay, BS; Muniza Sheikh, MS, MBA; Joy Esterlitz, MS; David Lynch, MD, PhD; Massimo Pandolfo, MD, FAAN; Amelie Gubitz, PhD; Codrin Lungu, MD; M. Carolina Mendoza-Puccini, MD; on behalf of the NINDS Friedreich’s ataxia CDE Oversight Committee and Working Groups.

16. May 2019 – American Academy of Neurology 71st Annual Meeting, May 4 – May 10, 2019, Philadelphia, PA. Multiple Sclerosis Common Data Element Review: Updates to the National Institute of Neurological Disorders and Stroke Multiple Sclerosis (MS) Common Data Elements Recommendations: 2018 MS Oversight Committee (OC) Review. Poster presentation. Authors: Katelyn Gay, BS; Ilar Edun, BA; Muniza Sheikh, MS, MBA; Joy Esterlitz, MS; Fred Lublin, MD; Ursula Utz, PhD; Codrin Lungu, MD; M. Carolina Mendoza-Puccini, MD; on behalf of the NINDS Multiple Sclerosis CDE Oversight Committee.

**NINDS CDE Presentations**

**Authors:** Robin Feldman, BS, MBA; Kristen Joseph, MS; Muniza Sheikh, MS, MBA; Joy Esterlitz, MS; Vanessa Noonan, PhD, PT; Lyn B. Jakeman, PhD; Carolina Mendoza-Puccini, MD; on behalf of the NINDS Spinal Cord Injury CDE Oversight Committee.

18. **May 2019** – American Academy of Neurology 71st Annual Meeting, May 4 – May 10, 2019, Philadelphia, PA. Stroke Version 2.0 Common Data Element (CDE) Review: Updates to the National Institute of Neurological Disorders and Stroke (NINDS) CDEs for Stroke. Poster presentation. **Authors:** Damon Collie MSHS; Katelyn Gay, BS; Muniza Sheikh, MS, MBA; Joy Esterlitz, MS; Jeffrey Saver, MD, FAHA, FAAN; Steven Warach, MD, PhD; M. Carolina Mendoza-Puccini, MD; Scott Janis, PhD on behalf of the Stroke V2.0 CDE Working Group.

19. **February 2019** – International Stroke Conference, February 4 – February 8, 2019, Honolulu, HI. A Stroke Version 2.0 Common Data Element Review: Updates to the National Institute of Neurological Disorders and Stroke Common Data Elements for Stroke. Poster presentation. **Authors:** Damon Collie, MSHS, Katelyn Gay, BS, Muniza Sheikh, MS, MBA; MS; Joy Esterlitz, MS; Jeffrey Saver, MD, FAHA, FAAN; Steven Warach, MD, PhD; M. Carolina Mendoza-Puccini, MD; Scott Janis, PhD on behalf of the Stroke V2.0 CDE Working Group.

**PRESENTATIONS IN 2018**

20. **December 2018** – American Epilepsy Society 2018 Annual Meeting, November 30 – December 4, 2018, New Orleans, LA. Keeping Recommendations Current: Updates to the National Institute of Neurological Disorders and Stroke (NINDS) Epilepsy Common Data Element Recommendations. **Authors:** Robin Feldman, BS, MBA; Joan Austin, PhD, FAAN; Jackie French, MD; Nicholas Barbaro, MD; Daniel Lowenstein, MD; Muniza Sheikh, MS, MBA; Ilar Edun, BA; Joy Esterlitz, MS; Vicky Whittemore, PhD on behalf of the Epilepsy CDE Oversight Committee and Working Groups.

21. **October 2018** – American Academy for Cerebral Palsy and Developmental Medicine 72nd Annual Meeting, October 9 – October 13, 2018, Cincinnati, OH. The National Institute of Neurological Disorders and Stroke (NINDS) Updates to the Cerebral Palsy Common Data Elements Version 1.0 Recommendations. Breakfast Seminar. **Authors:** Joline Brandenburg, MD; Robin Feldman, BS, MBA; Sherita Ala’i, MS; Joy Esterlitz, MS on behalf of the NINDS/AACPDM Cerebral Palsy CDE Oversight Committee and Working Groups.

22. **August 2018** – Neurotrauma, August 11 – August 16, 2018, Toronto, Ontario. Common Data Elements for Sport-Related Concussion: NINDS/NIH Harmonization of Common Language for Clinical Research Studies Poster presentation. **Authors:** Kristen Joseph, MA; Carolina Mendoza-Puccini, MD; Joy Esterlitz, MS; Katelyn Gay, BS; Muniza Sheikh, MS, MBA; Patrick Bellgowan, PhD on behalf of the Sport-Related Concussion CDE Working Group.
NINDS CDE Presentations

   **Authors:** Katelyn Gay, BS; Adam Bartsch, PhD, PE; David B. Camarillo, PhD; Carol Taylor-Burds, PhD; Muniza Sheikh, MS, MBA; Joy Esterlitz, MS; Kristen Joseph, MA; Carolina Mendoza-Puccini, MD; Patrick Bellgowan, PhD on behalf of the Biomechanical Devices in TBI CDE Working Group.

   **Authors:** Kristen Joseph, MA; Carolina Mendoza-Puccini, MD; Joy Esterlitz, MS; Katelyn Gay, BS; Muniza Sheikh, MS, MBA; Patrick Bellgowan, PhD on behalf of the Sport-Related Concussion CDE Working Group.

   **Authors:** Katelyn Gay, BS; Adam Bartsch, PhD, PE; David B. Camarillo, PhD; Carol Taylor-Burds, PhD; Sherita Ala’i, MS; Joy Esterlitz, MS; Kristen Joseph, MA; Carolina Mendoza-Puccini, MD; Patrick Bellgowan, PhD on behalf of the Biomechanical Devices CDE Working Group.

   **Authors:** Kristen Joseph, MA; Steven Broglio, PhD; Anthony Kontos, PhD; Harvey Levin, PhD; Kathryn Schneider, PhD; Elisabeth Wilde, PhD; Sherita Ala’i, MS; Joy Esterlitz, MS; Katelyn Gay, BS; Patrick Bellgowan, PhD on behalf of the Sport-Related Concussion CDE Working Group.

   **Authors:** Anthony Kontos, PhD; Steven Broglio, PhD; Harvey Levin, PhD; Kathryn Schneider, PhD; Elisabeth Wilde, PhD Kristen Joseph, MA; Sherita Ala’i, MS; Joy Esterlitz, MS; Katelyn Gay, BS; Carolina Mendoza-Puccini, MD; Patrick Bellgowan, PhD on behalf of the Sport-Related Concussion CDE Working Group.

**NINDS CDE Presentations**

**Authors:** Katelyn Gay, BS; Adam Bartsch, PhD, PE; David B. Camarillo, PhD; Carol Taylor-Burds, PhD; Muniza Sheikh, MS, MBA; Joy Esterlitz, MS; Kristen Joseph, MA; Carolina Mendoza-Puccini, MD; Patrick Bellgowan, PhD on behalf of the Biomechanical Devices in TBI CDE Working Group.

**Authors:** Anthony Kontos, PhD; Steven Broglio, PhD, FACSM; Kathryn Schneider, PT, PhD; Elisabeth Wilde, PhD; Kristen Joseph, MA; Muniza Sheikh, MS, MBA; Joy Esterlitz, MS; Katelyn Gay, BS; Carolina Mendoza-Puccini, MD; Patrick Bellgowan, PhD on behalf of the Sport-Related Concussion CDE Working Group.

**Authors:** Sarah Tanveer, BS; Sherita Ala’i, MS; Joy Esterlitz, MS; Michael L. Oshinsky, PhD on behalf of the Headache Version 2.0 CDE Working Group.

**31. April 2018** – American Academy of Neurology 70th Annual Meeting, April 21 – April 27, 2018, Los Angeles, CA. Common Data Elements (CDEs) for Biomechanical Devices used in Blunt Head Impact and Blast Exposure Dynamics: The National Institute of Neurological Disorders and Stroke (NINDS), National Institutes of Health (NIH) and Department of Defense (DOD) Version 1.0 Recommendations. Poster presentation.  
**Authors:** Katelyn Gay, BS; Adam Bartsch, PhD, PE; David B. Camarillo, PhD; Carol Taylor-Burds, PhD; Sherita Ala’i, MS; Joy Esterlitz, MS; Kristen Joseph, MA; Patrick Bellgowan, PhD on behalf of the Biomechanical Devices CDE Working Group.

**Authors:** Muniza Sheikh, MS, MBA; Joan Austin, PhD, RN, FAAN; Jackie French, MD; Nicholas Barbaro, MD; Daniel Lowenstein, MD; Sherita Ala’i, MS; Sarah Tanveer, BS; Joy Esterlitz, MS; Vicky Whitemore, PhD; on behalf of the Epilepsy CDE Oversight Committee and Working Groups.

**Authors:** Katelyn Gay, BS; Sherita Ala’i, MS; Joy Esterlitz, MS; Muniza Sheikh, MS, MBA;
NINDS CDE Presentations

Sarah Tanveer, BS; Kristen Joseph, MA; Elizabeth R. Unger, PhD, MD; Vicky Whittemore, PhD on behalf of the ME/CFS CDE Working Group.

34. **April 2018** – American Academy of Neurology 70th Annual Meeting, April 21 – April 27, 2018, Los Angeles, CA. Streamlining Clinical Research in Sports-Related Concussion: The National Institute of Neurological Disorders and Stroke (NINDS)/National Institutes of Health (NIH), and Department of Defense (DOD) Sport-Related Concussion Common Data Elements (CDEs). Poster presentation.
   **Authors:** Kristen Joseph, MA; Sherita Ala’i, MS; Joy Esterlitz, MS; Katelyn Gay, BS; Patrick Bellgowan, PhD on behalf of the Sports-Related Concussion CDE Working Group.

   **Authors:** Sarah Tanveer, BS; Sherita Ala’i, MS; Joy Esterlitz, MS; Michael L. Oshinsky, PhD on behalf of the Headache Version 2.0 CDE Working Group.

   **Authors:** Kristen Joseph, MA; Claudia Moy, PhD; Sherita Ala’i, MS; Joy Esterlitz, MS; Katelyn Gay, BS; Patrick Bellgowan, PhD on behalf of the Sports-Related Concussion CDE Working Group.

   **Authors:** Muniza Sheikh, MS, MBA; Sherita Ala’i, MS; Joy Esterlitz, MS; R. Loch Macdonald, MD, PhD; Jose Ignacio Suarez, MD on behalf of the SAH CDE Working Group.

**PRESENTATIONS IN 2017**

   **Authors:** Kristen Joseph, MA; Roger Kula, MD; Brandon Rocque, MD; Paolo Bolognese, MD; Cormac Maher, MD; John Heiss, MD; Allison Ashley-Koch, PhD; Dorothy Poppe, BA; Kaitlyn Esposito, BS; Joanne Odenkirchen, MPH; Robert Riddle, PhD; Sherita Ala’i, MS; Robin Feldman, BS, MBA; Ulrich Batzdorf, MD; Mark Luciano, MD, PhD

39. **September 2017** – Academy of Cerebral Palsy and Developmental Medicine (AACPDM), September 13 – September 16, 2017, Montreal, Quebec, Canada. The National Institute of Neurological Disorders and Stroke (NINDS) and American Academy of Cerebral Palsy and
NINDS CDE Presentations

Developmental Medicine (AACPDM) Cerebral Palsy Common Data Elements (CDE) Recommendations. Instructional Course.

Authors: Joline E. Brandenburg, MD; Eileen Fowler, PhD, PT; Robin Feldman, BS, MBA; Sherita Ala’i, MS; Joy Esterlitz, MS on behalf of the NINDS/AACPDM Cerebral Palsy CDE Working Groups.


Authors: Sarah Tanveer, BS; Sherita Ala’i, MS; Joy Esterlitz, MS; Katelyn Gay; BS; Michael L. Oshinsky, PhD on behalf of the Headache V2.0 CDE Working Group


Authors: Kristen Joseph, MA; Claudia Moy, PhD; Sherita Ala’i, MS; Joy Esterlitz, MS; Katelyn Gay, BS; Patrick Bellgowan, PhD on behalf of the Sports-Related Concussion CDE Working Group.


Authors: Katelyn Gay, BS; Adam Bartsch, PhD, PE; David B. Camarillo, PhD; Carol Taylor-Burds, PhD; Sherita Ala’i, MS; Joy Esterlitz, MS; Kristen Joseph, MA; Patrick Bellgowan, PhD on behalf of the Biomechanical Devices in TBI CDE Working Group.


Authors: Kristen Joseph, MA; Claudia Moy, PhD; Sherita Ala’i, MS; Joy Esterlitz, MS; Katelyn Gay, BS; Patrick Bellgowan, PhD on behalf of the Sports-Related Concussion CDE Working Group.


Authors: Michael L. Oshinsky, PhD; Sarah Tanveer, BS; Sherita Ala’i, MS; Joy Esterlitz, MS; Katelyn Gay, BS; Claudia Moy, PhD on behalf of the Headache V2.0 CDE Working Group.
**Authors:** Kristen Joseph, MA; Claudia Moy, PhD; Sherita Ala’i, MS; Joy Esterlitz, MS; Katelyn Gay, BS; Patrick Bellgowan, PhD on behalf of the Sports-Related Concussion CDE Working Group.

**Authors:** Joy Esterlitz, MS; Sherita Ala’i, MS; Robin Feldman, BS, MBA; Kristen Joseph, MA; Muniza Sheikh, MS, MBA; Claudia S. Moy, PhD; Sara S. Rue, MPH on behalf of the NINDS CDE Working Groups.

**Authors:** Steven Broglio, PhD; Kristen Joseph, MA; Sherita Ala’i, MS; Joy Esterlitz, MS; Kaitlyn Gay, BS; Patrick Bellgowan, PhD on behalf of the Sports-Related Concussion Working Groups.

**Authors:** Robin Feldman, BS, MBA; Joanne Odenkirchen, MPH; Sherita Ala’i, MS; Joy Esterlitz, MS; Tracy Burr on behalf of the NINDS/AACPDM Cerebral Palsy CDE Working Groups.

**Authors:** Sherita Ala’i, MS; Joanne Odenkirchen, MPH; Kristen Joseph, MA; Robin Feldman, BS, MBA; Kaitlyn M. Esposito, BS; Dorothy Poppe, BA on behalf of the Chiari I Malformation CDE Working Groups.

**Authors:** Sarah Tanveer, BS; Joanne Odenkirchen, MPH; Sherita Ala’i, MS; Joy Esterlitz, MS; Michael L. Oshinsky, PhD on behalf of the Headache V2.0 CDE Working Groups.
NINDS CDE Presentations

**Authors:** Kristen Joseph, MA; Joanne Odenkirchen, MPH; Sherita Ala’i, MS; Joy Esterlitz, MS; Sarah Tanveer, BS; Patrick Bellgowan, PhD on behalf of the Sports Concussion CDE Working Group.

**Authors:** Muniza Sheikh, MS, MBA; Sherita Ala’i, MS; Joy Esterlitz, MS; Liz Amos, MLIS; Christophe Ludet, MS; Joanne Odenkirchen, MPH; Jose Ignacio Suarez, MD on behalf of the SAH CDE Working Group.

**Authors:** Joanne Odenkirchen, MPH; Liz Amos, MLIS; Christophe Ludet, MS; Muniza Sheikh, MS, MBA; Sherita Ala’i, MS; Joy Esterlitz, MS; Jose Ignacio Suarez, MD on behalf of the SAH and Unruptured Cerebral Aneurysms CDE Working Group.

PRESENTATIONS IN 2016

**Authors:** Elizabeth R. Unger, PhD; Vicky Whittemore, PhD; Joy Esterlitz, MS

**Authors:** Joanne Odenkirchen, MPH; Tracy Burr, CAE; Sherita Ala’i, MS; Joy Esterlitz, MS; Robin Feldman, BS, MBA

NINDS CDE Presentations

Elements Version 1.0 Recommendations. Poster presentation.

Authors: Joanne Odenkirchen, MPH; Sherita Ala’i, MS; Robin Feldman, BS, MBA; Joy Esterlitz, MS; Muniza Sheikh, MS, MBA on behalf of the NINDS Myotonic Dystrophy CDE Working Groups.

Authors: Joanne Odenkirchen, MPH; Lyn Jakeman, PhD; MaryJane Mulcahey, PhD, OTR/L; Lawrence C. Vogel, MD; Muniza Sheikh, MS, MBA; Sherita Ala’i, MS; Joy Esterlitz, MS; on behalf of the SCI Pediatric CDE Working Group.

Authors: Joanne Odenkirchen, MPH; Scott Janis. PhD; Jeffrey L. Saver, MD; Steven Warach, MD, PhD; Thomas G. Broth, MD; Ralph L. Sacco, MD, MS, FAHA, FAAN; Muniza Sheikh, MS, MBA; Sherita Ala’i, MS; Joy Esterlitz, MS

PRESENTATIONS IN 2015

Authors: Joanne Odenkirchen, MPH; Joy Esterlitz, MS; Muniza Sheikh, MS, MBA

Authors: Joanne Odenkirchen, MPH; Sherita Ala’i, MS, Muniza Sheikh MS, MBA; Joy Esterlitz, MS on behalf of the NINDS Mitochondrial Disease CDE Working Groups.

Author: Joanne Odenkirchen, MPH

62. April 2015 – U.S. Food and Drug Administration Meeting Public Workshop on Assessment of Neurocognitive Outcomes in Inborn Errors of Metabolism and Advancing the Development of Pediatric Therapeutics: Assessment of Neurocognitive Outcomes, April 16 – April 17, 2015. Silver Spring, Maryland. NINDS Common Data Element (CDE) Project – Inborn Errors in Metabolism.
Author: Joanne Odenkirchen, MPH

63. April 2015 – American Academy of Neurology (AAN) 67th AAN Annual Meeting, April 18 –
NINDS CDE Presentations


Authors: Joanne Odenkirchen, MPH; Marybeth Montoro MPH; Sherita Ala’i, MS; Joy Esterlitz, MS; Elizabeth McNeil, MD, MSc; Robin Conwit, MD on behalf of The NINDS CDE CMD, FSHD and DM Working Groups.


Authors: Joanne Odenkirchen, MPH; Joy Esterlitz, MS; Sherita Ala’i, MS; Muniza Sheikh, MS, MBA on behalf of the NINDS Stroke Working Groups.

PRESENTATIONS IN 2014


Authors: Joanne Odenkirchen, MPH; Sherita Ala’i, MS; Amanda Suller; Marybeth Montoro, MPH, Muniza Sheikh, MS/MBA; Joy Esterlitz, MS on behalf of the NINDS Mitochondrial Disease CDE Working Groups.


Authors: Joanne Odenkirchen, MPH; Naomi Kleitman, PhD; Fin Biering-Sørensen, MD, PhD; Susan Charlifue, PhD, FACRM; Michael DeVivo, DrPH; Linda Jones, PT, MS; Sherita Ala’i, MS; Aria Lans, MPH on behalf of the NINDS International SCI CDE Working Group.


Authors: Joanne Odenkirchen, MPH; Sherita Ala’i, MS; Divya Nigam, BS; Joy Esterlitz on behalf of the NINDS Mitochondrial Disease CDE Working Groups.


Authors: Joy Esterlitz, MS; Sherita Ala’i, MS; Petra Kaufmann, PhD; Matthew McAuliffe, PhD; Matthew Beyers, MSc; Joanne Odenkirchen, MPH

NINDS CDE Presentations

Institute of Neurological Disorders and Stroke (NINDS) Spinal Cord Injury Common Data Elements (CDE).

**Authors:** Joanne Odenkirchen (NINDS) on behalf of the Spinal Cord Injury Common Data Element Working Group.


**Authors:** Wendy Galpern, MD, PhD

**PRESENTATIONS IN 2013**


**Authors:** Joanne Odenkirchen, MPH on behalf of the Spinal Cord Injury Common Data Element Working Group.

**PRESENTATIONS IN 2012**

72. **October 2012** – American Congress of Rehabilitation Medicine, October 13, 2012, Putting TBI Common Data Elements into Practice.


**Authors:** Wendy Galpern, MD, PhD on behalf of the Huntington’s Disease Common Data Element Working Group.


**Authors:** Andrew Charles, MD; Mitchell Brin, MD; Joanne Odenkirchen, MPH; Linda Porter, MD on behalf of the Headache CDE Working Group.


**Authors:** Wendy Galpern, MD, PhD on behalf of the Huntington’s Disease Common Data Element Working Group.


**Authors:** Jeffrey Saver, MD; Steven Warach, MD; Catherine Amlie-Lefond, MD; Joseph Broderick, MD; Colin Derdeyn, MD; Billy Dunn, MD; Mitchell Elkind, MD; Lawrence Fine, MD; Mary George, MD; Michael Hill, MD; Virginia Howard, PhD; Kennedy R. Lees, MD; David Levy, MD; Bo Norrving, PhD; Yuko Palesch, PhD; Lee Schwamm, MD; Pooja Khatri, MD; Stacie Grinnon, MS; Lisa Hunegs, MSW, MPH; Megan Otruba, BS; Scott Janis, PhD; Petra Kaufmann, MD; Joanne Odenkirchen, MPH.
NINDS CDE Presentations

**Authors:** Martin Delatycki, MD, PhD; Jennifer Farmer, MS; Kenneth Fischbeck, MD; Paul Kantor, PhD David Lynch, MD, PhD; Massimo Pandolfo, MD; Mark Payne, MD; Susan Perlman, MD; Jorg Schulz, MD; Robert Shaddy, MD; Subha Raman, MD; Petra Kaufmann, MD; Joanne Odenkirchen, MPH; Lisa Hunegs, MSW, MPH.

**Authors:** Lisa Hunegs, MSW, MPH; Alexandra Stout; Joanne Odenkirchen, MPH.

**PRESENTATIONS PRIOR TO 2012**

**Authors:** Caroline Tanner, MD, PhD; Karl Kieburtz, MD, PhD; Wendy Galpern, MD, PhD; Mahlon DeLong, MD; Dennis Dickson, MD; Jordan Elm, PhD; Tatiana Foroud, PhD; Cornelia Kamp, MBA; Anthony Lang, MD; Karen Marder, MD, MPH; Kenneth Marek, MD; Ronald Pfeiffer, MD; G Webster Ross, MD; Andrew Siderowf, MD; Daniel Weintraub, MD on behalf of the NINDS Parkinson’s Disease Common Data Element Working Group.

**Authors:** Stacie Grinnon, MS; Alexandra Stout, Brandy Fureman, PhD; Joanne Odenkirchen, MPH on behalf of the Epilepsy Disease Common Data Element Working Group.

**Authors:** The NINDS Epilepsy CDE Working Group; Brandy Fureman, PhD; Joanne Odenkirchen, MPH; Stacie Grinnon, MS, Alexandra Stout.

**Authors:** Wendy Galpern, MD, PhD on behalf of the Huntington’s Disease Working Group.

83. **September 2011** – World Congress on Huntington’s Disease; September 11 – September 14, 2011. Facilitating Clinical Research: The National Institute of Neurological Disorders and Stroke Huntington’s Disease Common Data Elements Project.  
**Authors:** Wendy Galpern, MD, PhD on behalf of the Huntington’s Disease Working Group.
NINDS CDE Presentations


**Authors:** Fin Biering-Sørensen, MD; Susan Charlifue, PhD; Michael J. DeVivo, DrPH; Stacie T. Grinnon, MS; Naomi Kleitman, PhD; Joanne Odenkirchen, MPH.


**Authors:** Wendy Galpern, MD, PhD on behalf of the NINDS Parkinson’s Disease Common Data Element Working Group.


**Authors:** Jeffrey Saver, MD; Kyra Becker, MD; Oscar Benavente, MD; Joseph Broderick, MD; Alexander Dromerick, MD; Pamela Duncan, PhD; Karen Johnston, MD; Chelsea Kidwell, MD; James Meschia, MD; Lee Schwamm, MD; Stacie Grinnon, MS, Lisa Hunegs, MSW, MPH; Scott Janis, PhD; Joanne Odenkirchen, MPH; Steven Warach, MD, PhD.

87. **May 2011** – 4th International Friedreich’s Ataxia Scientific Conference; May 5 – May 7, 2011. Developing Common Data Elements for Friedreich’s Ataxia Clinical Research

**Authors:** Martin Delatycki, MD, PhD; Jennifer Farmer, MD; Kenneth Fischbeck, MD; Wendy Galpern, MD, PhD; Lisa Hunegs, MSW, MPH; Paul Kantor, PhD; Petra Kaufmann, MD; David Lynch, MD; Kristy Miller, MPH; Joanne Odenkirchen, MPH; Massimo Pandolfo, MD; Mark Payne, MD; Susan Perlman, MD Jorg Schulz, MD; Robert Shaddy, MD; Subha Raman, MD.

88. **April 2011** – American Academy of Neurology (AAN); April 9 – April 16, 2011, National Institute of Neurological Disorders and Stroke, National Institutes of Health, Common Data Element (CDE) Project: Applying the General and Disease-specific CDEs to Clinical Research Projects Poster presentation.

**Authors:** Stacie Grinnon, MS; Kristy Miller, MPH; Petra Kaufmann, MD; Wendy Galpern, MD, PhD; Joanne Odenkirchen, MPH.


**Authors:** Stacie Grinnon, MS; Lisa Hunegs, MSW, MPH; Joanne Odenkirchen, MPH.


**Authors:** Stacie Grinnon, MS, Lisa Hunegs, MSW, MPH; Alexandra Stout, Brandy Fureman, PhD; Joanne Odenkirchen, MPH.
NINDS CDE Presentations

91. **September 2010** – caBIG Annual Conference; September 13 – 15, 2010: Harmonizing the National Institute of Neurological Disorders and Stroke (NINDS) Core Common Data Elements (CDEs) with the National Cancer Institute (NCI) Cancer Biomedical Informatics Grid (caBIG) Cancer Data Standards Registry and Repository (caDSR) Poster presentation.
   **Authors:** Stacie T. Grinnon, MS; Kristy Miller, MPH; Patti Shugarts, Yun Lu, PhD; Dianne Reeves, Joanne Odenkirchen, MPH.

   **Authors:** Stacie T. Grinnon, Kristy Miller, Patti Shugarts, Yun Lu, Dianne Reeves, RN, MSN; Joanne Odenkirchen, MPH.

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94. **May 2010** - Society of Clinical Trials Annual Meeting (SCT); May 16 – 19, 2010: National Institute of Neurological Disorders and Stroke (NINDS), National Institutes of Health (NIH), Common Data Element (CDE) Project: Developing Disease-specific CDEs Poster presentation.
   **Authors:** Kristy Miller, MPH; Stacie T. Grinnon, MS; Joanne Odenkirchen, MPH.