WriteClick: Editor's Choice

Editors' Note: Ms. Peay and Ms. Hesterlee of DuchenneConnect update readers on the purpose and features of the DuchenneConnect Registry. While they agree with authors Scully et al. on the need for tracking and reporting clinical outcomes for patients with Duchenne muscular dystrophy (DMD), they emphasize that this is not the Registry's primary purpose.

—Megan Alcauskas, MD, and Robert C. Griggs, MD

CAN OUTCOMES IN DUCHENNE MUSCULAR DYSTROPHY BE IMPROVED BY PUBLIC REPORTING OF DATA?

Holly L. Peay, Sharon Hesterlee, Hackensack, NJ: While we applaud the article by Scully et al.[1] regarding the need for a mechanism to report outcomes at clinics caring for patients with DMD, we would like to correct the following details about the DuchenneConnect Registry. These clarifications may be especially important given the limited methodologic description in the article. Study investigators and clinicians cannot "search the database for potential clinical trial participants." To protect registrants' confidentiality, registered professionals may receive only de-identified aggregated responses to registry questions.

Although the table reports a "negative-investigated" under "Genetic Confirmation," of our current population of more than 2,200 registrants, genetic confirmation has been made by DuchenneConnect's experienced, board-certified genetic counselor on 43%. This represents almost 1,000 individuals with curated genetic test results. Although the table reports "negative" next to "Public Reporting" and "Outcomes Reported," DuchenneConnect provides extensive reporting to patients, families, clinicians, and researchers through the Web site, newsletters, Webinars, yearly registry reports, presentations, and a peer-reviewed article. The DuchenneConnect patient report Clinic Survey received more than 200 responses by June 2012, not 27.

To be clear, these inaccuracies do not change the authors' conclusions that there is a need to track and report clinical outcomes for DMD. The DuchenneConnect Registry serves many primary purposes: trial feasibility and recruitment, education, and reporting aggregate demographic and general outcomes data. However, given the many stakeholders who rely on this registry for the purposes for which it was designed, we appreciate the opportunity to supply this correct information.

Author Response: Michele A. Scully, Rochester, NY; Valerie A. Cwik, Tucson; Emma Ciafaloni, Robert C. Griggs, Rochester, NY: We welcome the updates provided by Peay and Hesterlee regarding the DuchenneConnect Registry. The data obtained from this registry, as reported in Scully et al., were obtained directly from the DuchenneConnect Web site and a previous presentation published online. Since our article was accepted, the organization has provided an updated 2012 year-end report to include the new data referenced by Peay and Hesterlee. DuchenneConnect now has curated genetic test results for more individuals. Additionally, the extensive reports, Webinars, and articles that DuchenneConnect provides are helpful for others involved in the care of patients with DMD. However, we continue to believe that clinics caring for boys with DMD should publicly report standardized, de-identified data for all patients.

1. Scully C, Cwik VA, Marshall BC, et al. Can outcomes in Duchenne muscular dystrophy be improved by public reporting of data? Neurology 2013;80:583–589.

CAROTID DISSECTION FOLLOWING A GENERALIZED TONIC-CLONIC SEIZURE

Günter Krämer, Zurich: Drs. Child and Cascino are correct that their report of seizure-associated carotid artery dissection has not been described before.[1] However, there is an earlier report of vertebral artery dissection following a generalized tonic-clonic seizure.[2]

Author Response: Nicholas D. Child, Rochester, MN: We thank Dr. Krämer for bringing the earlier case report on vertebral artery dissection related to a generalized tonic-clonic seizure to our

attention.[2] Fortunately, these vascular events appear to be a rare adverse effect associated with seizure activity.

1. Child ND, Cascino GD. Carotid dissection following a generalized tonic-clonic seizure. Neurology 2013;80:1911.
2. Young CA, Chadwick DW, Humphrey PR. Extracranial vertebral artery dissection following tonic clonic seizure. J Neurol Neurosurg Psychiatry 1991;54:365–366.

CORRECTIONS

Ross syndrome: A lesson from a monozygotic twin pair

In the Clinical/Scientific Note "Ross syndrome: A lesson from a monozygotic twin pair" by M. Nolano et al. (*Neurology*® 2013;80:417–418), there is an error in Vincenzo Donadio's affiliations, which should have read: IRCCS Institute of Neurological Sciences, Bologna, Italy. The authors regret the error.

High pro-BNP levels predict the occurrence of atrial fibrillation after cryptogenic stroke

In the article "High pro-BNP levels predict the occurrence of atrial fibrillation after cryptogenic stroke" by M. Rodríguez-Yáñez et al. (*Neurology*® 2013;81:444–447), there is an error on page 445. The confidence interval of the patients who developed atrial fibrillation should read as follows: (1,140 [486–2,118] vs 220 [72–652] pg/mL, $p < 0.0001$). The authors regret the error.

Vitamin B_6-responsive epilepsy due to inherited GPI deficiency

In the Clinical/Scientific Note "Vitamin B_6-responsive epilepsy due to inherited GPI deficiency" by I. Kuki et al. (*Neurology*® 2013;81:1467–1469), there is an error in "Results and discussion." The second mutation in the third sentence should read as follows: c.2497_2498del. The authors regret the error.

Teaching Video Neuro*Images*: Perioral myoclonia with absences in a 12-year-old boy

In the article "Teaching Video Neuro*Images*: Perioral myoclonia with absences in a 12-year-old boy" by S. Sharma et al. (*Neurology*® 2013;81:e116), there is an error in the main text paragraph. The word "oxacarbamazepine" should have been spelled as follows: oxcarbazepine. The authors regret the error.

Author disclosures are available upon request (journal@neurology.org).

Carotid dissection following a generalized tonic-clonic seizure

Günter Krämer and Nicholas D. Child

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