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UNITED STATES SUES THE NORTHERN ILLINOIS SPECIAL RECREATION ASSOCIATION, ALLEGING VIOLATION OF AMERICANS WITH DISABILITIES ACT FOR REFUSING TO ADMINISTER EPILEPSY MEDICATION

CHICAGO — The United States filed a civil lawsuit today against the Northern Illinois Special Recreation Association (NISRA), which provides recreational activities for adults and children with disabilities, alleging that it discriminates against participants with epilepsy by refusing to administer potentially life-saving anti-seizure medication. The lawsuit alleges that NISRA's policy violates the Americans with Disabilities Act and seeks a court order requiring NISRA to administer the medication in the event a participant has a seizure.

NISRA, based in Crystal Lake, is a group of 13 park districts and municipal recreation departments that provides a variety of year-round programs for children and adults with disabilities. NISRA staff routinely dispense medication to participants, including epinephrine auto-injector shots to children experiencing allergic reactions and asthma medication to children with asthma, in addition to feeding children with gastrostomy feeding tubes. The association also serves children and adults who have been diagnosed with epilepsy, a neurological disorder with a tendency for recurrent seizures that affects about three million people in the United States.

“This lawsuit seeks to require NISRA to make a reasonable modification to its policies to administer a life-saving medication to participants with epilepsy who need it so that they may enjoy

the same services, programs, and activities as other individuals with and without disabilities,” said Gary S. Shapiro, Acting United States Attorney for the Northern District of Illinois. Mr. Shapiro announced the lawsuit with Thomas E. Perez, Assistant Attorney General for the Justice Department’s Civil Rights Division.

The lawsuit was filed on behalf of two youths with epilepsy who have participated in NISRA’s programs in the past and wish to continue to do so in the future. One is 17-year-old female who lives in McHenry County and has suffered approximately 30 tonic-clonic seizures (commonly known as grand mal seizures) over the last 10 years, some lasting longer than an hour, which can be life-threatening.

The youth’s physician has prescribed Diastat AcuDial (Diastat), which is the only FDA-approved medication for out-of-hospital treatment of emergency, prolonged epilepsy seizures. Diastat is a gel form of diazepam, a central nervous system depressant, that is used to stop seizures and prevent brain damage or death. Diastat works most effectively if administered within five minutes of the onset of the seizure, and the longer it takes to administer the medication, the less effective it is in stopping an ongoing seizure. Diastat is administered rectally using a pre-filled plastic syringe with a flexible plastic tip, which allows the medication to act quickly and safely. There are no adverse side effects when administered incorrectly or when the person is not actually suffering a seizure. Diastat was developed to be administered by people without medical training, such as parents, teachers, camp counselors, and caregivers, according to the civil complaint.

The teenager’s physician has developed a seizure plan that describes what her seizures look like, how to treat them, when to call 911, and directs that Diastat be administered immediately upon

the onset of a grand mal seizure. The girl has received Diastat approximately 20 times over the last 15 years, and her mother, father, and siblings have all administered the medication at least once.

In 2007 and 2008, the girl participated in NISRA's summer camp program and several other programs during the school year. At that time, NISRA agreed to administer Diastat if needed, but at no time was it actually required. After the 2008 summer camp, NISRA changed its policy to no longer administer Diastat, and adopted a policy to follow the participant's seizure plan as closely as possible, but calling 911 instead of administering the medication, resulting in a dangerous delay.

The girl's parents asked NISRA to continue accommodating their daughter by administering Diastat but NISRA refused. The association offered instead that the girl's parents could hire a caregiver or send a family member to accompany her and administer the medication if needed; otherwise, NISRA would call 911. As a result, the girl did not attend any NISRA programs in 2009 or 2010 because her parents did not want to risk their daughter having a grand mal seizure without assurance that she would promptly receive Diastat before paramedics might arrive.

Despite NISRA's policy, the girl's parents decided to take a chance and enrolled their daughter in the 2011 summer camp because she had not experienced a grand mal seizure in five years and had been entirely seizure free for six months. Although they remained concerned about not having Diastat immediately available, the parents did not want their daughter to miss the opportunity to develop socially and have fun. The girl attended NISRA's summer camp last year without incident.

Since camp ended, however, the girl has had several additional grand mal seizures. She "desperately wants to participate in future NISRA summer camps because it is the only summer camp available to her. Given the recent onset of her prolonged seizures, however, NISRA's

continued refusal to administer Diastat makes [her] participation in any NISRA camp or program very risky to her health,” the lawsuit states.

The second youth is an eight-year-old girl who lives in Crystal Lake and was diagnosed with epilepsy in 2005. Her physician also has prescribed a treatment plan that includes promptly administering Diastat. The girl registered to participate in the Crystal Lake Park District’s 2011 summer camp and asked that a NISRA aide be allowed to administer the medication if needed. NISRA refused the request and informed the girl’s parents that the aide would only monitor their daughter for signs of a seizure and would call 911 if a seizure occurred.

Despite NISRA’s policy, the girl’s parents allowed their daughter to attend camp last summer because she had not had a grand mal seizure in four years. The girl had no seizures while attending camp or since then, but her parents remain concerned about what will happen if she needs Diastat at camp in the future and cannot get it.

The lawsuit requests the Court to rule that NISRA’s policy violates the ADA and seeks an injunction requiring the association to administer Diastat to participants in its programs as medically required and prescribed by the participant’s physician.

The government is being represented by Assistant U.S. Attorneys Patrick Johnson and Harpreet Chahal.

The lawsuit contains merely allegations of unlawful conduct. In civil cases, the government has the burden of proving the allegations by a preponderance of the evidence.

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