

Community walk planned to shed light on rare disorder

By TRACY BURTON

for the Daily News

Kathy Leonard is doing what she can to raise awareness about Angelman Syndrome (AS) — a rare genetic disorder that sometimes is misdiagnosed in young children as cerebral palsy or autism.

For the past several weeks, Leonard has been busy planning an AS Walk set for 9 a.m. Saturday in Midland's Plymouth Park. Registration opens at 8 a.m. and participants are invited for coffee and pastries prior to the 2.5-mile walk.

Afterward, parents will have an opportunity to visit with other parents while their children play on the playground.

"I want people to know that a support network exists for those affected by Angelman Syndrome," Leonard said. "I hope this walk will just help by meeting others who are going through some of the same issues they are."

All proceeds from Saturday's walk will benefit the national Angelman Syndrome Foundation to support further medical research. Its mission is to advance the awareness and treatment of AS through education and information, research, support and advocacy.

Angelman Syndrome occurs in one of every 15,000 live births. Individuals with AS present symptoms such as developmental delays, lack of speech, seizures,

inappropriate laughter and walking and balance disorders.

In 1965, Harry Angelman, an English physician, was the first to identify the disorder, but the condition was considered extremely rare back then, and many physicians doubted its existence. The first reports from North America appeared in the early 1980s.

Leonard knows first hand what it's like to have a child misdiagnosed as her oldest daughter — now 19 — was treated for several years for what doctors had believed was cerebral palsy but later realized was actually AS after a genetic test became available.

"This just shows how valuable scientific research is," said Leonard, of Rhodes. "Now there is a test, but when my daughter was young, this didn't exist."

Doctors also told Leonard it was OK to have children without worries about complications, however, her two other children — now 10 and 13 — also have been diagnosed with AS.

"Some days are not easy at all, but we get by," Leonard said. "We have a lot of support, which is very helpful."

Eileen Braun, executive director of the Angelman Syndrome Foundation, said Leonard has been a tremendous resource in bringing more awareness to the state of Michigan.

"She has been a wonderful and tireless advocate," Braun said.



THOMAS SIMONETTI | tsimonetti@mdn.net

Rocky Leonard, right, 10, works with Wendy Lyons on an activity at his home. Leonard, along with his two sisters Amanda, 19, and Angela, 13, have been diagnosed with Angelman Syndrome — a rare genetic disorder sometimes misdiagnosed in young children as cerebral palsy or autism.

A total of 28 AS walks are planned throughout the U.S.

"Each year, we continue to grow, which is exactly what we wanted to do," Braun said. "The walks are so important

because they are our single largest fundraising event and they bring awareness to communities."

To learn more about Angelman Syndrome visit www.angelman.org