

New Palestine Reporter

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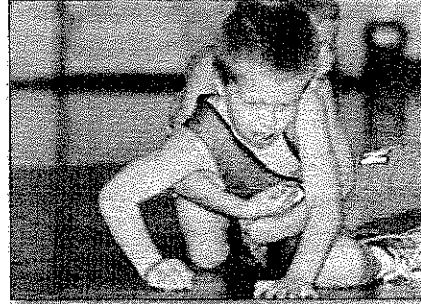
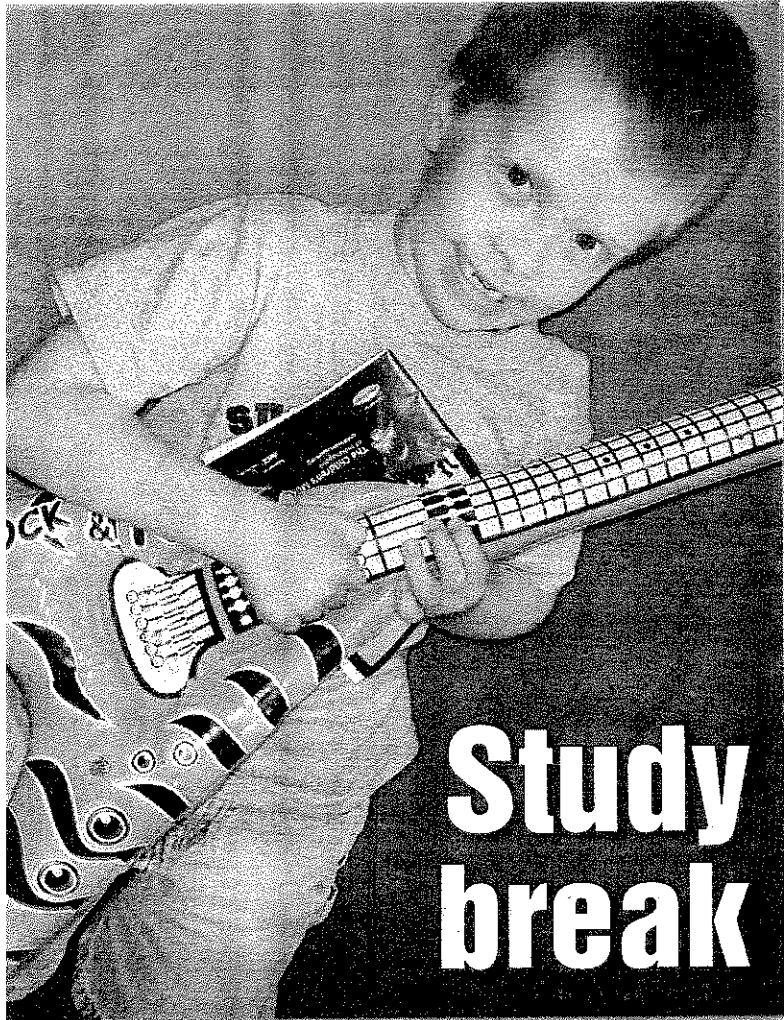
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FRIDAY,
March 25, 2011

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Family hopes Spring Break trip sheds light on son's condition

By **KRISTY DEER**

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Like most families during spring break, the Gumberts packed their bags in anticipation for their big trip.

Unlike most families getting ready for a fun vacation getaway, the Gumberts are headed east to Boston.

Their son Danny has been invited to take part in a one-of-a-kind research study at the Children's Hospital at Harvard University.

While Danny is a bright, active 7-year-old attending Brandywine Elementary School, he has a problem with speech.

▶SEE STUDY, PAGE 20

Photo provided
Potential: Danny Gumberts (left) is taking part in a special study at Harvard University that his parents hope can give them some insight into Danny's condition. Danny enjoys wrestling (above) and other childhood activities.

DOWN TO BUSINESS

Biz Town holds real-world lessons for elementary students

Page 9



INSIDE THIS WEEK

Obituaries	2
Tribute	3
Opinion	4-5
Calendar	7
Church	8
Schools	9
Sports	16-17
Classified	18-19

'They're trying to link anything that they can':
 Audrey and Sarah Gumberts, Danny's older sisters, do not suffer from the chromosome issue he does, but researchers at Harvard will test them as well to see if they can find additional insight into the condition.



Photo provided

▶ Study

Continued From Page 1

Danny originally was diagnosed with autism spectrum disorder, but his parents didn't feel that was correct.

Karen and Greg Gumberts had their son's chromosomes tested and found he has a micro-deletion in his 16th chromosome, causing speech problems.

"The study is to research the potential risks for developmental problems," Karen said. "We're very excited about the opportunity."

A chromosome 16p deletion means part of one of Danny's chromosomes is missing.

"It's just a tiny piece," Greg said. "It's a new find with a test they started doing just a couple of years ago."

The lost genetic material can contain important instructions for the brain or body, which can cause developmental delay, some learning and behavior difficulties, and possible health problems.

Fortunately, other than speech difficulties, Danny is considered a normal child.

While his parents say the speech problems make Danny seem a little immature for his age, he brings home good grades from his special needs class at BES and takes part in wrestling and other childhood activities.

"He's always had speech, he just can't articulate and communicate effectively what he's trying to get across," Karen said.

"He gets 100 on his spelling tests

almost every week," Greg added.

The family was thrilled to find the Harvard study online and to be selected as the first family for the research, which will not cost them a penny.

Danny will have a complete evaluation, which includes medical and behavioral assessments, and studies also will be conducted on his sisters, who have no difficulties.

"They're trying to link anything that they can find doing a study on the whole family," Greg said.

They're hopeful the research will give them knowledge to understand ways to help Danny get caught up with fellow students by middle school age.

"As they integrate kids with Down syndrome into general education classes, I'm kind of hoping that will be a possibility for Danny down the road," Karen said.

The belief that everything happens for a reason drives the family. They lost their first child, son Jacob, in 1999 to a genetic disorder.

However, the knowledge they learned from that loss convinced them to have Danny's chromosomes tested.

"We wouldn't have known to get Danny tested if we had not gone through that," Karen said.

The Gumberts are hoping their story might encourage other parents with children who have been diagnosed with autism to have the child's chromosomes checked.

Knowing a wrong label can follow a child throughout his or her development, getting a correct diagnosis, they said, is important.

"Some parents accept the autism

diagnosis and say, 'that's what it is,' and really we want other parents to know their child may have another diagnosis that is causing the developmental delay," Karen said.

She said she believes during the next five years the number of those diagnosed with autism will decrease, while the figure for those with chromosome issues will increase.

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