



## **Independence the goal for Downs Syndrome initiative**

By John Tapley, Staff writer, Ingersoll Times, July 16, 2008.

If Kristov Loebus has a job making pizza 10 years from now, it'll be a dream come true for him and his father, Andy.

It's a dream of independence for Kristov and other children with Downs Syndrome that drives the Downs Syndrome Research Institute (DSRI) which the elder Loebus helped launch four years ago.

"Why can't they do what everyone else is doing?" he asks. "We always believe that they can do things, not that they can't, and they're forever surprising us. Ultimately our goal is to give them independence."

Based in London, DSRI is a parent-driven, not-for-profit initiative that runs a one-month summer program for children with Downs Syndrome, from preschool age through high school. Using innovative strategies in teaching methodology, the focus is on literacy and numeracy.

"Early intervention in speech and communication is paramount for our kids," says Loebus who works as a teacher at St. Mary's and volunteers as director of DSRI. "If they're not understood, they have a hard time achieving things in life."

Serving the region, DSRI has grown since it was established four years ago when there were eight participants. This year, 50 children are expected to enroll in the program including some from Ingersoll.

Curriculum is developed jointly by everyone involved including educational assistants, volunteers, teachers and therapists.

"Everyone contributes in setting up the program," says Loebus.

Each of the participants is thoroughly assessed before each session and their skill development is closely tracked throughout the program. A detailed report card is provided to each of them.

“The whole team comes together and sets goals for the kids,” says Loebus.

The program’s three groups – preschool, elementary and high school – each have their own theme. This year, the preschoolers will be focused on making the transition to Kindergarten, the elementary theme is animals and the high school group is looking at reaching out to others.

Others are seeing the benefits of the program and satellite operations are being established in Peterborough and Alberta.

“Our model has proven very effective,” says Loebus, who received an achievement award from the Ontario Downs Syndrome Association.

DSRI, which has a relationship with McGill University, is also looking to partner with a local school board to run a pilot program based on its methods and eventually establish a school around its model.

“Things are looking good for our growth,” says Loebus.

Recognizing that children with Downs Syndrome learn differently, one of DSRI’s goals is to help teachers learn how to reach them.

Raising awareness and changing public perception about people with Downs Syndrome is another key goal.

“If you raise the bar and you have high expectations from our kids, they can meet them,” says Loebus.

Giving children with Downs Syndrome the skills to transition from school to work and independence to become equal contributors in society is what it’s all about and Loebus has a 10-year plan for the program. To gauge its success, he only has to look at his son Kristov, 11, who dreams of one day having a job making pizza.

“When he’s 21, he’ll be ready to go into the world of work,” Loebus says. “When he’s 21, I want him to have a job.”

Independence includes opportunities in business and practical experiences, says Loebus who has an idea for starting a restaurant operated by people with Downs Syndrome and other special needs people.

While the program continues to grow year-to-year, fund-raising is an ongoing effort. While volunteers play a big role in running the program, payroll for professional staff like speech therapists will be \$70,000 this year. Receiving support from groups like the Knights of Columbus and Masons, Loebus says any contributions are helpful. Tax receipts are available.

“It’s always a struggle,” he says, adding that it’s well worth it. “We look forward to doing great things. It’s a blessing because hanging out with these kids is a gift and working with them is a gift.”