

# Living With Juvenile Diabetes

*How two local kids learn to cope with the disease*

By SHARON MACGREGOR

**P**eg Wood of Bloomingburg distinctly recalls driving home from a family vacation five years ago when her then-8-year-old son Tyler turned extremely pale. His lips were purple-black and his breath had a fruity odor. His blood was tested at the emergency room in Orange Regional Medical Center. He then went into a diabetic coma and was transferred to Westchester Medical Center for a five-day stay until his insulin level could be stabilized. Tyler has Type 1 Juvenile Diabetes.

One year ago, 5-year-old Julianna Fiero of Winterton was constantly thirsty and inexplicably losing weight. After a blood test revealed her sugar level to be 565 – the normal range is 80-120 – she was sent to Westchester Medical Center. Julianna's mom, Vivian, now brings her to a pediatric endocrinologist at Columbia Hospital's Diabetes Center once every three months for treatment for Juvenile Diabetes.

The Juvenile Diabetes Research Foundation (JDRF) website states that as many as 3 million Americans may have type 1 diabetes. Each year, more than 15,000 children are diagnosed with diabetes in the U.S. That's 40 children per day.

According to JDRF, "a person's pancreas produces little or no insulin. Although the causes are not entirely known, scientists believe the body's own defense system attacks and destroys the insulin-producing cells in the pancreas."

But once the diagnosis is made,



## *Support for kids with juvenile diabetes*

The local JDRF Chapter and Orange Regional Medical Center will work together thanks to the efforts of Vivian Fiero (above left, with her daughter, Julianna, lower right). Fiero holds a support group at Orange Regional Medical Center the 3rd Wednesday of every month. In this forum, parents can meet and learn from each other the day to day living tips a health care provider simply may not have experienced and allow the children to meet. For more information about this group and the meetings, please call 845-342-7555. The Hudson Valley branch of the JDRF is located in Wappingers Falls and can be reached at 845-297-8600.

the real question for families is: what happens now?

In one year, Vivian Fiero says, "Julianna has had about 2,190 finger sticks. We check her blood every time she eats. At school she gets checked before she eats, before gym and before she gets on the bus. She is now on the insulin pump and life is getting a little easier."

At school, the teacher may remind Julianna it is time for her to check before lunch or snack. "I'm getting more used to [pricking my finger on the meter in the classroom]," Julianna says, "and I don't really mind if people watch, as long as it isn't too many."

If her levels are too high or too

*(Continued on Page 32)*



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## JUVENILE DIABETES

(Continued from Page 30)

low, someone will walk with Julianna to the nurse's office. One day in September, her reading was in the 300s – more than double the normal range – so the nurse called Vivian to advise her.

In instances like that, Julianna must receive insulin through her pump and be rechecked every hour to ensure her levels drop to the normal range.

Julianna's insulin pump attaches directly to her body, acting as both a computer/calculator and medication administrator. When she eats, Julianna uses buttons on the pump to provide additional insulin, called a bolus.

The bolus covers the carbohydrate in each meal or snack. If she eats more than planned, she (or a parent) can program a larger bolus of insulin.

If Julianna has high blood glucose levels before she eats, she gives a correction or supplemental bolus of insulin to bring it back to her target range.

Vivian explains that after Julianna does a finger prick on the glucometer, the pump will ask if she is going to eat. If she says yes, the pump asks how many carbs and it will calculate how much insulin to deliver.

### Diabetes "no big deal" to Bloomingburg teen

If you ask Tyler about his diabetes, he may tell you, "It's no big deal." He and his family have learned to check levels, adjust medication through an insulin management system, which is similar to an insulin pump (without the tubes) and recognize which activities are most likely to cause his sugar levels to drop.

Tyler is an active 8th grade student at Circleville Middle School

who loves to play catcher on his baseball team, scuba dive, swim and ride his ATV. Swimming burns the most calories of these activities and requires an extra trip to the school nurse if he swims for gym class. The nurse may check his levels on the insulin pump and ensure proper dosages have been dispensed.

Julianna enjoys horseback riding and cheerleading, and checks her own sugar levels before each practice. The challenges of diabetes are felt most when classmates or friends are celebrating special occasions with cupcakes or other sweets.

Though she strongly wants to simply fit in and not be noticed for being different in any way, Julianna is aware of her diet limitations at a young age.

Before going to a friend's house or birthday party, mom Vivian will advise the parents of Julianna's condition.

"You have to build a team between yourself and the school," says Vivian. "You also have to know the parents of your child's friends. Awareness makes it easier. Julianna simply does not want to feel like an outcast or different."

Vivian has created a sheet that is sent to the school each day with Julianna. On the sheet are specific foods selected from the cafeteria menu with exact serving amounts and carbohydrate quantities.

If she is bringing lunch, all of the carbohydrates have been calculated to make the administration of insulin easier via the pump. At any time, the pump can be checked to ensure proper amounts were dispensed throughout the school day.

### Home support is key in managing the disease

Of her three brothers, Julianna has received the most support to date from Jonathan, who is only

(Continued on Page 34)

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(Continued from Page 33)

eight. He was not sure how to react at first, but in time has become encouraging and understanding. Jonathan is very aware of the signs his sister may exhibit, such as a pale face or if she seems shaky, and has walked her to the nurse's office at school last year. Older brothers Kevin Fiero and Nicholas Terzo are also compassionate at home.

It may be because Tyler is a few years older and has had time to adjust, but mom Peg explains, "He simply leaves class to go to the nurse's office if he feels his levels are too high or low. He can test himself and knows he cannot indulge in ice cream or soda at a

friend's house. He really tries to not let it be an issue."

The Wood family includes parents Russell and Peg as well as Tyler's older brother, Russ. None of the family has a history of diabetes, and all have learned about the effects of food, sugar and insulin in relation to Tyler's daily routine.

According to JDRF, "Despite rigorous attention to maintaining a meal plan and exercise regimen, and always injecting the proper amount of insulin, many other factors can adversely affect efforts to tightly control blood-sugar levels including: stress, hormonal changes, periods of growth, physical activity, medications, illness/infection, and fatigue."

Julianna is a patient of Barney Softness, MD, a pediatric endocrinologist at Columbia Presbyterian.

Dr. Softness has explained to the Fieros the changes Julianna may face as she grows. During the teen years, fluctuating hormones can also be counted on to interfere with the ability to easily manage diabetes. Blood sugar levels are expected to be more erratic, especially during menstrual cycles, which may require more frequent testing and insulin adjustments.

Finding others who are going through the same experience is a challenge. Fiero only knows of one other child at Otisville Elementary, where Julianna is a student, and Wood is aware of only two others at Circleville Middle School with the same disease.

However, both families participated in the JDRF Walk for a Cure event in Newburgh and have walked in other towns as a way to both raise fund for juvenile dia-

betes research and meet other families.

The Fieros held a dinner dance last summer that raised \$3,700 and will be donated on behalf of Julianna's team at the walk in September. \$4,200 was raised this year by the Fieros.

The Otisville Elementary School hosted a walk on October 10th and JDRF will come to the school for an educational presentation and while the kids walk to cure diabetes. The organization's slogan for the event is, "Kids helping Kids."

Last year, Team Tyler raised \$3,200, and the 18-member group looks forward to increasing their donation for 2009.

*Sharon MacGregor is a freelance writer living in Sullivan County. Her work has also appeared in Hudson Valley Life magazine.*



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