WALK TO CURE DIABETES

Marissa's Mermaids

Dear Friends:

Since Marissa, our 6 year-old daughter, was diagnosed in Sept. 2005 with Type 1 Diabetes, she has had **4620 finger pricks** to draw blood and **1095 injections**. Now, she is attached to an insulin pump 24 hours a day. Type 1 (or Juvenile) Diabetes is a chronic, debilitating disease affecting every organ system – it is an autoimmune disease where the body attacks its pancreas and permanently destroys the cells that make insulin. Once Type 1 Diabetes arrives, it becomes a life-long condition. We need to find a cure, and, with your help supporting the Walk to Cure Diabetes, we will.

Like nearly 3 million Americans with Type 1 Diabetes, Marissa has a lower projected lifespan by 14 years and is more likely to suffer blindness, amputation, heart disease, kidney disease, nerve damage, and 2-4 times more likely to have a stroke or heart attack. Every year, 13,000 children are diagnosed. **INSULIN IS NOT A CURE – IT IS MERELY LIFE SUPPORT**. At times when Marissa is most upset, with tears in her eyes, she says, "I wish I could take my diabetes and throw it in the trash can." Occasionally, she asks, "When are the doctors going to find a cure?"

To manage Marissa's diabetes, we have the impossible struggle of balancing carbohydrates, insulin, and physical activity with uncontrollable variables such as illness, growth, exercise-level, excitement, and stress. Every day offers Marissa the risk of a drastic low blood sugar causing seizure or possibly death. It could only take *one mistake* on one morning or one afternoon or one night… or it might simply involve a random event from her body.

Marissa is so brave as we poke her finger to draw blood 8-12 times each day including routine checks at midnight and 3am. Every carbohydrate at every meal or snack must be counted. Then the carbohydrates must be perfectly balanced immediately through injections or an insulin pump to *attempt* to imitate the way your and my pancreas works. (See page 2 for 24-Hours in the Life of Marissa.) There are no exceptions and there is never a day off!

Because of groups like the Juvenile Diabetes Research Foundation (www.jdrf.org) and research scientists around the world, our daughter has a chance to live a healthy, albeit high-maintenance, life. Here's how:

- JDRF's exclusive focus is finding a cure for diabetes.
- Their organization is amazingly efficient with 85% of all donations going directly to research!
- Our donations and those by our friends are effectively utilized to the exact goal of a Type 1 diabetic.

Major research advances have occurred in the past few years! Diabetes has been cured in mice in at least 4 ways and various human trials are beginning. Scientists legitimately believe a cure is possible before Marissa loses this life-long battle. We ask you to help us find a cure by sponsoring or joining us on Saturday, **Sept. 29, 2007** at Granite Park at 5800 Granite Parkway, Plano, TX 75024 at 8:45 am. Last year, Marissa's Mermaids raised $14,431 as 71 walkers proudly walked by her side for the cause! We need your help to make an even bigger impact this year. Your contribution might make the difference in the one research laboratory where "the cure" will be achieved!

- Please join the Marissa's Mermaids team or donate at http://walk.jdrf.org/walker.cfm?id=86695071.
- Click "**Donate to this Walker**" and JDRF will accept credit card donations online! Your contributions are tax deductible.
- If you prefer to write a check, please make checks payable to JDRF and send to Ken and Lisa Conway.
- Please forward Marissa's newsletter to your friends.
- Finally, **please ask your organization** (or you as an individual) **to sponsor** and obtain recognition for your generosity. When you click "Join this Team," simply click "Register as a Captain" under Marissa's Mermaids to enable others to sign up and select you as their captain.

Your donation could change the lives of nearly 3 million Americans (mostly children) and save our daughter. Thank you!

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24-hours in the life of a Type 1 Diabetic

Consider the following 24-hour period that Marissa battled. Most days are better than this. Correct Blood Glucose (BG) range should be between 80 and 150 to be in normal range (like our bodies).

- 11:20am – BG 65 (treated for low blood sugar by giving 15 Grams of sugar-snack because her BG was lower than 70) – This "low" had made her tired and *sluggish* and caused her legs to "*feel funny*". She bounced back within 20-25 minutes, felt normal and had a great lunch and afternoon.
- 3:48pm – BG 275 high blood sugar (*headache*, acting a bit *irrational*, was *sweaty*) – treated "high" by giving extra insulin through her insulin pump (extra insulin given above what her body normally requires)
- 5:00pm Dinner – BG 61 (treated "low") – She had become very *tired* and *lethargic* and her legs "felt funny". Apparently her body had over-responded to the extra insulin a little over an hour ago.
- 10:00pm (while asleep) – BG 257.
- 12:00 Midnight – BG 269 (corrected the high BG by having her pump inject a higher amount of insulin than is typical while she was asleep.
- 3:00 am – BG 53 – She was low, and lows can be a dangerous situation ***(sometimes causing seizures or even a diabetic comma leading to death)***. Gave her 15 gms of sugar with a juice box.
- 3:20 am – BG 58 – Her BG had only raised 5 points in 20 minutes. Suspended and disconnected the pump. Gave her another 15 grams of sugar through a juice box to treat the continued "low" condition.
- 3:40 am – BG 137 – BG into a good range; Resumed pump operation.
- 8:00 am (Breakfast) – BG 306 – Treated high BG in addition to her normal "extra" insulin required to balance her greatest carbohydrates. (*Not* how you want to start your day).

Marissa had **14 finger pricks** to draw blood and test her BG during the above **24 hours**. Those wild BG swings wear her body out and can cause long-term complications.

2 other Crazy Days

There are plenty of examples we can share where uncontrollable events occur. Here are 2 examples where 1 mistake or controllable factor can occur and affect Marissa.

Wrong Chocolate Milk

One mistake in counting carbohydrates has a huge impact on Marissa's blood sugar control. One day we accidentally switched Marissa and Megan's chocolate milk for breakfast. Marissa's chocolate milk has 5 grams of carbs per 8 ounces. Megan's chocolate milk has 28 grams. So when we gave Marissa her breakfast bolus to balance 40 grams of carbohydrates, we should have given her insulin to balance 63 grams. At school that morning, Marissa was not herself. Her teacher had to ask her to settle down. Her teacher was puzzled because this had never happened with Marissa. Marissa couldn't sit still, was hot and sweaty, and certainly in no mental state to learn. Her blood sugar spiked into the 400s that morning.

Eat Your Cookie – and don't ask for Vegetables!!!

Marissa insisted on having a cookie with icing one day at the mall. Well, we have the pump and that allows flexibility in eating patterns, so we said, "Fine, we'll get you a cookie." She insisted the cookie wasn't too big. The manager indicated the cookie had about 35 grams. Well, you guessed it…. Marissa ate one-fifth of the cookie and wasn't hungry anymore. Yet, we had given her an insulin bolus for the whole thing already. Think of the irony of this statement, "You may not leave this table until you finish that cookie… and don't ask me for any green beans or vegetables because those don't have enough carbs!" We ended up persuading her to drink a 15-gram juice box. But, that wasn't enough. As expected, she turned pale and very lethargic a little more than an hour later… we knew it was coming, treated the low, and moved on.

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Common Questions you have Asked

How/when did she get it?
Marissa was sick on Memorial Day weekend 2005. It seemed like a typical sickness that any kid gets and she was "well" shortly thereafter. Yet, many researchers believe a virus triggers the auto-immune response in some people. Researchers don't know if it is one particular virus… if they knew which virus, there might already be a cure. During the healing process the immune system mistakenly turns on its own beta cells that produce insulin in the pancreas. Once triggered, the auto-immune attack becomes permanent and never stops. About 2 months after Memorial Day 2005, we noticed Marissa was losing weight and looking frail. Soon thereafter, she was officially diagnosed with Type 1 Diabetes. We don't know for certain that the Memorial Day illness caused Marissa's diabetes but it seems quite plausible. We simply know that there is nothing we could have done to prevent whatever event triggered her auto-immune attack.

Is it hereditary?
Once one family member is diagnosed, there are higher odds that other siblings or future children will be diagnosed. Yet, dating back through Marissa's Great-Great Grandparents on both sides of the family, there are no incidents of Type 1 Diabetes in our family.

Can she eat sugar?
Yes. Unlike Type 2 Diabetes where diet and exercise require careful control of sugar intake, this is not an absolute requirement for a Type 1 Diabetic. As long we measure the number of carbohydrates in any food (including high sugar foods), we can balance those carbohydrates with the appropriate amount of insulin required.

Now that you have the pump, you don't have to check her blood anymore, do you?
Wrong. Unfortunately, she will have to check her blood for the rest of her life. She will need someone to test her blood in the middle of the night even as an adult since the risk of a severe low blood sugar, if unattended, can lead to death. We spoke to a lady recently who wakes up every night to test her husband's blood sugar.

Once you get her insulin pump settings stable, then she stays regulated, right?
True, the pump helps regulate the amount of insulin that enters Marissa's body with different settings every hour around the clock. Yes, the pump offers greater potential to regulate the exact amount of insulin required for every situation. Yet, once you get every setting for every hour of every day "correct", Marissa might go through a growth spurt causing new settings for the pump. The body reacts randomly every single day to insulin-level, growth, hormones, exercise level, etc. The pump is truly a blessing. Yet, the reality is that these random events occur multiple times every week.

Marissa with Walkers Trevor and Brandon Summers