• Low blood sugar at birth, dismissed as big baby/gestational diabetes.
• NICU for 2 weeks on IV.
• Sent home with very low blood sugars and incomplete diagnosis.
• Our research found CHOP HI center and we got him to CHLA and transfer to CHOP.
• PET scan – diffuse, ocreotide/dextrose not enough, so surgery.
• Still hypoglycemic after pancreatectomy, so went home on Octreotide.
• Hated the g-tube and resisted using it, but at around 9 months gave in – D20 at night, Octreotide during the day.
• Made sugars more stable and life more manageable.
• Slowly were able to wean off Octreotide and then D20.
• In 2010.
• At age 4 or 4½, totally off meds and dextrose.
• Removed g-tube 6 months later.
• Visit to pancreas at CHOP.
I know many worry about school. I did too.

There were and continue to be challenges – both in terms of logistics and care issues and also worries about Max feeling “different.”

But, a lot of beautiful moments have come from this HI journey.

I came across this video and think it is fitting to share.

Preschool graduation.
• Despite my determination to make it not so, Max was officially declared diabetic just over a year ago.
• He currently gets one shot of long-acting insulin a day (at dinner time). At some point he’ll probably need pre-meal bolus insulin as well, but for now his A1C has been great.
• School is a challenge in some ways. Small school. No nurse. But they adapt. He is very self-sufficient and responsible about it (Amy Sommers’ advice). Camp was easier last year because of diabetes diagnosis. Diabetes camp.
• Loves school and learning.
• Plays tons of sports and engages in all activities totally normally. Aspires to be an NBA player.
• I included photo in upper right because combines his two big passions.

• Going through photos and prepping for this reminded me of the struggle. The emotion of that is still pretty close to the surface for me, even though I forget about it on a regular, day-to-day basis. But mostly I feel so fortunate and proud and joyful – to think how amazingly he is doing now and how uncertain and scared we were back then.
• Always was a good eater, although baby food was a big struggle.
• Once he was able to pick food up with his fingers and feed himself it was much easier.
• Video from when he was 5 shows his enthusiasm for food.