April 8, 2007

Via Facsimile and First Class Mail

Counsel
Counsel's Law Firm

Re: Max Doe and Public School District

Dear Counsel,

We read with great disappointment your letter which arrived via fax mid afternoon on April 1, 2007. We had hoped, and indeed asked, for specific steps the school intended to take to address the situation surrounding the school's failure to follow the health plan and 504 plan for Max Doe and to ensure that his life and health is not jeopardized again in the future. Instead, the entire six page letter was full of specious denials, blame-shifting, and unfounded accusations towards a family, including a vulnerable child. For these reasons, we are prepared to move forward with a lawsuit in federal court, if the steps delineated at the end of this letter are not taken.

But first, to correct the misstatements and obfuscation.

Violations of the DIHP & 504 Plan

While you assert that your client has been instructed to "follow to the letter" the DIHP and 504 plan, your letter documents – and in some cases concedes – numerous violations in complying with both of these documents. Let me go through several of these violations which I'll roughly categorize as follows.

Response to blood sugar levels (BG levels)

Some basic information—information the school and staff would have learned had the administration provided them with proper training—glucometers, the devices used to measure blood sugar (glucose), only indicate the blood glucose (BG) level at one exact moment in time—the BG level could be different one minute later. An explanation by the school that proper care was not given because Max's blood glucose (BG) level was one point away from an action point is unsound and reflects a fundamental misunderstanding of diabetes disease management.

Diabetes is a serious, life-long condition with no cure. In consideration of the young age at which Max developed the disease, the risk of long term complications are extreme and the

school's cooperation with his care is imperative. Max has severe hypoglycemic insulin reactions (i.e. low blood sugar) and they can happen very quickly. He has suffered multiple grand mal seizures and many episodes of unconsciousness due to low blood sugar levels. This has happened with numbers between 20 and 70. Diabetes can cause blood glucose levels to be too high or too low, both of which affect the student's ability to learn as well as seriously endangering the student's health – immediately and in the long term.

Insulin does not address low blood sugar; it is used to treat high blood sugar and given with food because otherwise the food would make the BG levels rise. Physical activity, including outdoor recess, gym class and the indoor activities that were discontinued, also lower the BG level. The effect of physical activity has been discussed several times in meetings and should have been covered at the training that was provided to the administration and staff. Note that at numerous places in the DIHP and 504 plan recess and gym are referred to together.

The DIHP (Ex. A.) clearly indicates that Max's target glucose range is 80-150, as does the 504 plan, both on the page entitled "Response to Results" (Ex. B), and on the one page document provided to the school by the Does at the school's request and incorporated by reference in the 504 plan by the school ("Scheduled BG Checks,"[1] Ex. C):

Target BG Range:	80-150
Before Lunch:	80-130
Post Meal:	140-160

If BG is less than 80 then give 2 glucose tabs & snack. Recheck in 15 minutes.

If BG is less than 120 then give student a snack.

If BG is between 120 and 150 then send student back to class. If snack is requested, use Bolus Wizard (i.e. insulin).

If BG is more than 150 then deliver a "High Blood Sugar Bolus" using Bolus Wizard.

If BG is less than 150 prior to gym class (i.e. physical activity including outdoor recess) give snack, no bolus.

An exception that a bolus is not given unless the BG level is more than 200 before physical activity is highlighted in bold. Also, as the DIHP emphasizes in bold and all capital letters, "If glucose is less than 120MG/DL before gym, give 15 gms fast acting carb" (i.e. glucose tabs). (Ex. A.) Responses to blood sugar levels as set forth in these documents (and prior versions before that) were discussed extensively at the 504 meeting in January and in communications in February. Specifically, as asked by Principal Anderson and clarified by the parents, these are separate instructions; each BG check is not dependent on one another.

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[1] A prior copy of this document had been signed by the physician, and the school had the audacity to question the authenticity of the signature.

The principal violated the DIHP and 504 plan by her admitted actions in sending Max to outdoor recess alone without a snack when his BG level was 102 on March 10 at 11:35.

- The DIHP emphasizes that if the BG level is below 120 before physical activity, Max needs glucose tabs. (Ex. A.) This was not done.
- The 504 plan states, "If less than 120 then give snack." (Ex. C; see also Ex. B (giving instructions of steps to take if BG level is below 120.) This was not done.
- The 504 plan states that if Max's blood sugar is less than 150 prior to physical activity, he needs a snack, but not insulin. (Ex. C.) This was not done.
- The DIHP and 504 plan indicate target BG levels that cannot possibly be achieved by having Max do physical activity without a snack when his sugar is already low. (E.g. Ex. A, Ex. C.)

These violations put Max at risk of unsafe low blood sugars, and demonstrate the principal's lack of knowledge, lack of training, and/or inability to adequately care for Max. Not surprisingly, as a result of these actions, Max did indeed return from recess in under an hour with dangerously low blood sugar (71).

The principal violated the DIHP and the 504 plan numerous times by her admitted actions on March 10 at approximately 12:20 when she gave Max insulin when his BG level was 71:

- The 504 plan states, "If BG is lower than 80, call parents to consult." (Ex. B.) This was not done.
- The 504 plan ("Communication," Exs. D & E[2]) states that if anyone other than the nurse is administering insulin, the parents must be called. The principal is not the nurse, and is therefore required to call *prior* to the administration of insulin, not after. This was not done.
- The Scheduled BG Checks indicates that action to address low blood sugar needs to be taken if less than 80, and if less than 120. (Ex. C.) This was not done.
- The DIHP states that Max's target glucose range is 80-150. (Ex. A.) 80 and under is below the target range, and requires immediate action. 70 and below should raise a red flag that an emergency situation is arising or already occurring. (Ex. A.) The DIHP

[2] While in correspondence on April 1 the school intimated that the requirement that the Does be called if anyone other than the school nurse administer insulin was a "change" to the prior version of the 504 plan, any such suggestion is simply not true. From the beginning, it has always been a requirement that if anyone other than the full time school nurse, Susan Johnson, administer or supervise a bolus, the parents must be called prior to the administration, regardless of whether Max presses the button or an adult presses it. Calling after the bolus is too late; once in the body, insulin cannot come back out, thus the requirement.

notes that the information given is considered to be guidelines and to consult the parents. This was not done. Per the physician's orders, if there were any confusion or misunderstanding (which is absolutely not even alluded to in your letter) about the notation on the DIHP referring to emergency BG levels below 70, what should happen between 70 and 80, about the different nomenclature used to refer to physical activity, or any other instructions, the principal should have contacted the parents. This was not done.

Insulin administration at BG levels of less than 80, specifically without a fast acting glucose source, place Max in an immediate, life threatening situation. Supervision is imperative when BG levels are low (i.e. less than 80) as low levels directly affect the neurological system, cognition, and the ability to globally function. The school knows Max uses Rapid Acting Insulin, which begins acting in less than 10 minutes and continues to lower blood sugar for approximately two hours. Administration and staff have previously been informed that Max suffers from seizures and has had seizures at 70 and below. Supervision with regards to food consumption is therefore necessary, regardless of the typical level of cooperation demonstrated by the child.

Your repeated inferences that because Max "bolused himself" the principal is therefore not responsible for the administration of insulin is not a satisfactory response. The student is 7 years old and supervision, especially when his BG level is dangerously low, is required for a reason. You do not deny that Max had to wait at the end of the lunch line (even though he had been given fast acting insulin at a dangerously low BG level) and that no one watched to ensure he ate entire lunch (even though his blood sugar was so low it could have affected his ability to understand he needed to eat his entire lunch). Note that if his blood sugar had been this low when the school nurse was present he would have been walked to the front of the line and the nurse would have verbally told the lunch staff and the lunch supervisors that he is running low that day. With respect to the principal's claims that Max was accompanied to lunch, we won't argue about it here, but credibility concerns have been raised with respect to the person making this defense.

Next, Max was sent to recess at approximately 12:40. Knowing that he was experiencing low blood sugar, he was too scared to play with the other kids and instead stood by the school wall before deciding to go inside around noon. His fears were fully founded. Not only had he been bolused by the principal when his blood sugar was already low, the insulin he had been given was still acting, and, the pump was scheduled to give a basal dose at noon. Again, insulin and physical activity drive blood sugar down. Contrary to the school's suggestion that the principal called the parents due to an unscheduled check, the principal called because Max asked her to because he was scared. The school acknowledges that Max needed to talk to his mother for "reassurance." On the phone, the principal indicated that she did not know what steps to take. Yet by the school's admission, Max reported "to the office indicating that he was feeling low." According to the DIHP, a blood sugar check must be performed when the child is not feeling well. (Ex. A.) It was not until Mrs. Doe instructed the principal to check the blood sugar that she took this step.

<u>Calling the parents was absolutely not a problem</u>; misrepresenting the reason for the call was unnecessary.

After Max ate two glucose tabs per Mrs. Doe's instructions, he returned to recess. Principal Anderson's account that she "waved to the lunch supervisor and pointed to Max … [and] the supervisor waved back" did not indicate anything with regards to Max's medical needs. No matter the intent, waving is not an adequate way to indicate the concerns about the low BG levels he had been experiencing.

Furthermore, *the principal has responded inappropriately to high blood sugar levels and in violation of the DIHP and 504 plan.* The school does not deny that Max's BG level at 12:20 on February 23 was 428, that at least 25 minutes later the principal still had not called the parents to let them know, that she had been informed that his unusually high levels raised concerns that there might be an occlusion, and that she did not call the parents at 2:00 to let them know his BG level. Shockingly, especially given that 150 is the high end of Max's target levels and given that the DIHP flags 300 as an unusually high level requiring additional action and monitoring and parental participation, the school claims that Max's mother has indicated in the past that this was, in the principal's words, "good for Max."

This exhibits a gross misunderstanding of diabetes, and is further proof that the training provided by the school is inadequate and the principal is not an appropriate person to care for Max. Blood glucose levels of 556 or 428 are not "good for Max" or any other human being. The DIHP clearly states that BG levels greater than 300 two times within two hours require specific steps to remedy the situation and that the parents are to be contacted. The pump itself advises the caregiver to "check for occlusion." None of these steps were followed. In fact, Principal Anderson had to ask Max what an occlusion was.

The principal further admits that she mixed up BG levels of 102 and 120 and was corrected by the child. (At 102, Max should have been given a snack because he was under 120, and as the principal acknowledges, the parent should be called before the bolus because she is not the nurse.) The principal admitted to supervising his bolus, asserting she "watched him enter his BG as 102 and bolus himself." Yet according to his pump (data from both the glucometer and pump are routinely downloaded), he was bolused at a BG of 120. This demonstrates negligent supervision in both confusing BG levels and in supervising an incorrect bolus. Making a mistake is one thing. But first denying that it was even a mistake and then shifting the blame to a child highlights the Doe's concerns that the principal is not an appropriate person to provide care for Max.

Parents' decision making

The school questions several times the parents' decision making with respect to what you describe as when "Mrs. Doe has called and instructed them to do things, such as override the insulin pump or not bolus when provisions in the plan would call for such an action." On both occasions when this occurred, the school had called Mrs. Doe—for the former at Max's request, and for the later when the secretary called Mrs. Doe.

Calling the parents is not a problem; misrepresenting who called who is unnecessary.

The need for these decisions was created by the school's failure to follow the DIHP and the 504 plans. *And the parents' decision making in response to the school's failure was entirely appropriate and consistent with the DIHP and 504 plans.* The parents are responsible for all pump programming and adjustments.[3] The physician stated in the DIHP that the parents set the basal rates, set the insulin to carbohydrate ratio, routinely change the settings as necessary, have information about the current settings, and should be consulted for specifics. *Refusing to contact the parents for the most current instructions, settings, and specifics violates the DIHP.*

The decision to override the pump settings has occurred only when the mother came to the school to administer the insulin and was in response to incorrect bolusing by the school's caregiver, specifically, when cupcakes for a classmate's birthday were not considered or included in the lunchtime bolus prior to administering insulin.[4] *This violates the DIHP and 504 plans.* ("Non-routine Situations," Ex. F; see also Ex. A, Ex. B, Ex. C, etc.) Max was told he could not eat the cupcake. Fortunately, the school complied with Max's request that the school call his parents which allowed the parents the opportunity to correct the school's mistake. With a proper bolus at that time, Max could eat the treat along with his classmates. The pump is programmed to refuse multiple boluses within certain periods of time because it "interprets" multiple boluses as a mistake made in bolus administration (for example if the person with diabetes could not remember if she had already given herself insulin). Thus, to intentionally give two boluses, the pump settings must be manually overridden. The school does not have instructions or permission to override the pump settings. Any actions or decisions with regards to this must be made and have been made by the student's parents.

Regarding decisions "not to bolus when the plan calls for such provisions" is an inaccurate account of the events that occurred on March 10, the day in question. The school secretary called to inform the parents of a 96 BG level. The district indicated the phone call was simply given "as a courtesy." However, *to not call would have plainly been a violation of the DIHP and 504 plan*. Max requires a snack when he is below 120 (he does not have to request it), and all snacks must be bolused. Any administration of insulin not by the school nurse must be

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[3] How the pump functions and is operated is exactly the type of information the representative from Medtronics would have provided to the school administration and staff had the school not refused this offer.

[4] Note that this violation of the DIHP and 504 plan occurred *after* my letter sent to you dated March 22. Your suggestion that the "problems . . . occur when circumstances arise in which the parents have advised the District staff to take actions that deviate from what is specified in the doctor's order" is patently false. Problems occur when the school violates the DIHP and 504 plan.

preceded by a call to the parents. (See e.g. Ex. A, Ex. B, Ex. D.) As the secretary was the only person at school to do this, the call to the parents was mandatory.[5]

The parent did indeed instruct her to give a snack, and bolus, subtracting 5 grams of carbohydrates for the bolus administration because Max had been and was currently low. *This is entirely consistent with the DIHP and 504 plan* (BG less than 120 means he needs a snack; and under DIHP parents are to be contacted for ratios, current settings, and specifics of guidelines). The secretary was extremely apologetic, explaining that she was comfortable supervising BG checks, but she was not comfortable or trained to administer insulin. The mother thanked the secretary for her honesty. She instructed the secretary to send the student back to class and she would be there to administer his care as soon as possible. Upon arrival at the school, the parent again thanked the secretary and explained that this is exactly why appropriate training needed to be provided to the school staff. *The school violated the DIHP and 504 plan by not having someone at the school properly trained to administer insulin.*

The next BG check is scheduled for 3:30 pm. The school admits that this check was administered at 3:40 pm, and that Max's BG level was 195—well outside of his target range and well beyond the point at which he needs insulin, and that the parents were not called at that time because the secretary was too busy, and that Max was sent to the library without being bolused. At no time does the school state a substitute nurse was actually present to administer insulin. *The school violated the DIHP and 504 plan by having no one in the school to administer insulin, failing to contact the parents to inform them he needed insulin but no one was available to administer it, failing to communicate in a timely manner, and failing to provide appropriate training.* (See Ex. B, Ex. C, and Ex. A.)

Contrary to the school's dubious claim that another nurse "would be coming over" to the school (even though the school simultaneously argues that no action was necessary in response to the 2:00 BG level, obviating the need for a substitute nurse to "come over"), there was still no one in the school building to administer insulin hours later. The school secretary did not call the parent with the results until after 4:00, nor had another school nurse been called to administer the insulin that had been needed 30 minutes earlier. The secretary apologized for the delay and not being able to call sooner, indicating that she had become busy with other tasks and she was the only person in the school's office. The mother indicated that Max should have been bolused under the provisions of the DIHP, but at this time she could not get to the school prior to dismissal and that she would administer the insulin when she picked the student up from school. There was no time for another nurse to get to the building prior to dismissal. The secretary apologized again. Had insulin been administered at 3:30, or even at 3:40, or even at 4:00, Max's blood sugar would never have spiked to the dangerous level of 397. Yet no one was present in the school to do this.

School staff

[5] The school both expects to be lauded for its "courtesy" (page 2, Apr. 1 letter) in calling at this time (even though it was not really a courtesy but required), and yet at the same time accuses Mrs. Doe of initiating this call to the school and directing it to "deviate" from the doctor's orders (page 5, Apr. 1 letter).

Since we are turning to communication next, I'll take this opportunity to make two points. First, every interaction between the parent and secretary was cordial and calm. At no time did the secretary indicate that another school nurse would be called to the building to administer insulin, nor was she cut off in any way from explaining such a story. The parents appreciate the professionalism and courtesy shown by the secretary.

Second, I am not sure what you hope to gain in your April 1 letter by rehashing the situation in which Max was forcibly tested. The parents brought their concerns to the school's attention and provided written information on February 12 as to how to handle a situation in which Max refuses any aspect of his diabetic care. The school responded, agreeing that they would work with Max in the future to help him understand how important compliance with his regime is and that they would call the parents if they needed assistance. I did not raise this situation at all in my March 22 letter. However, once again, we are now forced to reply.

The incident of Max's BG being forcibly checked was brought to light after he came out of the school crying and scared indicating that the school nurse "forced him" to check his BG when it was unnecessary. The next morning the parents went with the child to discuss the incident with the principal. Ms. Anderson, in front of the child, told the parent to "document your concerns and refer them to your attorney," and then proceeded to question the student's honesty before sending him off to class. *The principal violated the DIHP and 504 plan by refusing to communicate with the parents about Max's care.* (See e.g. Ex. D.) Working with Max to secure his compliance and to encourage self-sufficiency was also discussed at length at the prior meetings with the school.

In contrast, this incident was discussed and resolved between the parents and the school nurse. As the parents explained to the nurse, they did not believe that the nurse's actions were in malice, but that Max's trust and cooperation was imperative. This is the first and only time that Max has cried or in any way refused his diabetic care in this way. The nurse has taken steps to obtain and secure a trusting relationship with Max and the parents. The school nurse has made great strides in her understanding of and ability to address the care of a child with diabetes. The parents and the school nurse have developed a mutually respectful, cooperative and successful relationship.

Communication

The 504 plan states that "ongoing communication when needed will occur." (Ex. D.) The DIHP states that "parents need to be consulted." *The principal violated the DIHP and 504 plan by refusing to discuss Max's care with the Does and undeniably repeatedly referring them to their attorneys to address their concerns about his care.* Furthermore, your statement that "timely communication has been maintained" is just plain untrue. Consider, for example, the numerous times that the parents have had to contact the school because they have not received a call at a time they know a call should be coming (such as at during a blood sugar check or when there was concerns about an occlusion); the number of times the school has simply failed to contact the parents at all (such as when Max's BG level was below 80 or not being bothering to

returning phone calls to them); as well as the times actions were inappropriately taken before the parents were called (such as administering insulin).

Traveling

Max is to travel with a buddy or adult. This is especially imperative when Max has low blood sugar. ("Learning Environment Accommodations," Ex. G.) *The school has violated the DIHP and 504 plans by allowing Max to travel through the school alone.* The school does not deny that Max was sent to recess alone with a BG level of 102 without a snack on March 10. Additionally, the school claims that Max was accompanied in various situations when he should not have been traveling alone. Again, the school attempts to take advantage of Max's young age to dispute his credibility. On March 26, after receipt of my letter to you highlighting this deficiency, staff was reminded again that Max should not be walking the hallways alone, especially when his blood sugar is low. While we applaud the school's efforts to remedy its failings, and hope that they remedy the other deficiencies in the future, to attempt to do so by casting aspersions on a child is unwarranted and out of line.

Birthday treats/special events

We discussed this at length during the 504 meeting in January. Max is to have birthday treats along with the other children and is to participate in special events. Treats are not to be sent home with Max nor is he to be given a substitute snack. Obviously, proper bolusing must accompany the consumption of snacks. (Ex. F; see also Ex. B, Ex. C, Ex. A). *Failing to notify the parent of the birthday treat and then telling the student the birthday treat would be sent home violates the 504 plan and the DIHP.* Not to mention, excluding a young child from participating in his best friend's birthday celebration is just plain insensitive.

Emergency situations

As we addressed in the January meeting and again in the objection to the 504 plan dated January 10, 2007, the school's emergency plan for Max incorporated in its 504 plan must list a specific sequence of steps and it needs to include the administration of glucagon as the first step. This means that a person trained in the emergency administration of glucagon must be at the school at all times Max is present. This is in full accordance with the current DIHP. Namely:

> **GLUCAGON_1.0_MG IM ER KIT TO BE GIVEN ONLY IF STUDENT UNABLE TO TAKE P.O. LIQUIDS WITH SEVERE HYPOGLYCEMIA . . . COMA, SEIZURES OR VOMITING.** After injection, turn child on their side child may start vomiting. **CALL 911, THEN NOTIFY PARENT.** NEVER LEAVE CHILD UNATTENDED. TRANSPORT TO NEAREST ER.[6]

[6] DIHP dated February 6, 2007, emphasis in original.

Yet the school has decreed that "in the event of emergency care needs, 911 will be called and a parent contacted" ("Testing Part 2," Ex. H, sent via letter dated February 2 to Does). The school's unilateral decision to disregard the physician's direct orders is inexplicable, irresponsible, and could jeopardize Max's life and health.

Severe hypoglycemia (low blood sugar) is very dangerous. In an emergency, glucagon must be given *immediately*. There is no time for the paramedics to arrive, let alone a nurse from another school. Waiting for someone to arrive, including 911, could literally mean the difference between life and death. The body begins to shut down during a severe hypoglycemic reaction – first he cannot swallow, then he cannot breathe, then he starts seizing. Significant, irreparable brain damage would be certain if Max were left unconscious, seizing for this extended amount of time.

The school does not, and cannot, dispute that there have been times when no one was at the school who was trained to administer glucagon. *This is a violation of the DIHP.* And we have no reason to believe that even on days when the principal is present, but the nurse absent, that the principal is a qualified person to administer glucagon or otherwise respond appropriately in an emergency. Having someone allegedly "on their way" to the school is insufficient, as is designating the principal as a backup person.

Release of Confidential Medical Information

Here's the last we will say on the issue of the medical release: The Does did not agree to sign a medical release at the meeting in January, and they will not now sign a blanket medical release.

First, Max's physician, a specialist and department head of pediatric endocrinology at the Hospital, has specifically advised the parents to not sign the release. Second, the physician has directed the school to talk to the Does about Max's care. Third, the physician's office does not even have the most current pump settings or knowledge about Max's most recent BG levels or his daily regime. If the school were to call the physician, the physician would just turn around and call the parents herself to get the exact same information the school could have asked the parents for! As is clearly stated by the physician in the DIHP:

> **Insulin Pump Dosage Information:** Rapid Acting Insulin either Humalog or Novolog (setting subject to change) Basal Rates and Insulin:Carb Ratio **are routinely changed by parents as necessary. Parents will have current settings.**
>
> **Physician Consent:** Above information is considered to be guidelines, **parents need to be consulted for specifics.**[7]

[7] DIHP dated February 6, 2007, emphasis added.

Refusing to communicate with the parents and instead demanding a release violates the DIHP. Fourth, it is utterly illogical that the school would first refuse to accept the offer for the endocrinologist's office to hold a training to teach school personnel about diabetes in general and Max's care in particular, and then the school would turn around and demand permission to speak to the physician's office about diabetes in general and Max's care in particular. Given this, it is hard to escape the conclusion that the school is seeking a medical release solely in order to second guess the parents' decision making and to cut them out of communication.

At the January 504 meeting, which I attended,[8] the parents were asked and agreed to provide a "clear copy" of the physician's medical plan. This is the only communication with the physician my clients agreed to, and the school memorialized it in the 504 plan dated January 3, 2007 ("Mom will have clear copy provided to school team by her M.D." Ex. B.). The physician and parents complied with this request by transmitting a "clear copy" of a DIHP dated January 9, 2007. The school requested the physician provide "clarified language" (see letter dated February 2, 2007) and another medical plan was developed to once again respond to the school's questions.

While the Does and Max's physician have complied with the school's multiple requests for clarification, *it must be noted that the number of requests once again demonstrates problems with the competence of the administration to follow and execute a DIHP*. In fact, "clarification" requests have required the physician to provide four separate "revisions" of the medical plan this school year alone. The revised plans are dated 9/12/06, 10/3/06, 1/9/07 and 2/6/07. The physician's office has indicated that they have never seen a situation like this and the Public School District is the only school district that has requested clarifications or revisions of one of their patient's health plans.

Allegations about Conduct of Parents

Your client has attempted to escalate this situation with untrue and offensive allegations that the parents showed up "unannounced," were "disruptive," and "hostile." Even though the school's story about the parents' alleged conduct is completely irrelevant to the care that the school provides or fails to provide for Max, we cannot in good conscience let these statements stand. Please note that according to the school's handbook, "parents and other visitors are welcome in our schools."[9] Parents are requested to report to the school office. On March 11, the

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[8] We have absolutely no problem with the school communicating with the Doe's about Max's care—it is of course, required by the DIHP, in Max's best interest, and encouraged by all of us on this side. However, it was not appropriate for the school to ask the Does to waive their rights with respect to Max's confidential medical information in an communication that was not sent to their counsel, not even as a courtesy copy. I was quite frankly surprised when I received a copy of the school's February 2nd letter from my clients. Given that the Does had specifically *revoked* their previously granted permission, the school's understanding of our position on this matter is crystal clear. Additionally, since an amendment to 504 plan was attached to the February 2nd letter, it would have been appropriate to copy me on such correspondence as well as all other correspondence relating to the 504 plan including amendments. I choose to treat this, however, as an oversight on the part of your clients, and as we have been attempting to resolve this matter amicably I have not raised it previously. Again, please do not take this to mean that the school should not communicate freely with the Does about Max.

[9] Public School District Handbook.

Does complied with these requirements. They did not expect the principal to "drop all of her other scheduled activities and responsibilities," but rather waited patiently while she made her morning announcements. The parents expressed concern about events from the prior day, and the principal invited them into her office, mentioning that she had an assembly that morning.

However, as the Does attempted to explain how her actions did not follow the medical plan and why they were dangerous, the principal immediately referred them to "document your concerns and refer them to your attorney." The Does explained that this was an immediate concern for their child's safety and it was imperative to review and clarify appropriate care. As your letter acknowledges, the principal repeated that they should "document your concerns and refer them to your attorney" then opened her office door and told them that she had an assembly starting in 30 minutes. *This is in violation of the 504 plan that "ongoing communication when needed will occur"* (Ex. D.) Per the school's own written policy, the Does have every right to discuss concerns about Max's care with the principal, and in fact, given her misunderstanding of diabetes and Max's care, she should have been asking them for information much sooner. *To not do so was a violation of the DIHP that the parents should be consulted about Max's care.*

The school nurse was standing in the doorway of her office (not attending to a student as was suggested) and the parents requested that she review the medical plan with the principal. The nurse said that she was not aware of what had occurred the day before. The parents told her that Max had been sent to outdoor recess at 100 and bolused at 71 for 78 carbohydrates. The nurse stated, "I would not have done that," and she stepped into her office to retrieve Max's medical book. As confirmed by your letter, rather than express a willingness to address Max's care, the principal told the parent that they were welcome to take Max home if they felt that his life was in danger. The Does indicated that Max could be left at school under the nurse's care and that their concerns were with the reckless care provided by the principal. Then, for the first and only time, the principal told the parents to leave the school grounds. They immediately left.

While the parents were understandably frustrated by the principal's refusal to discuss proper care for Max, at no time did they yell or disrupt school operations. To describe the incident as a "tirade" is a gross exaggeration. There is even a witness to these events, although we are not prepared to disclose more about this person. Furthermore, at no time was the written request for adjustments to be made to the 504 plan discussed at all. There was no request for "unilateral" adjustments of any kind to either plan. The parents have extensive professional experience navigating the special education system and are well aware that requests must be made in writing and any responses must be made in writing. Had the changes not been put in writing, the principal most likely would have directed them to do so, via their attorney. The principal does not have the authority to make any adjustments to any student's medical plan.

Again, we are not interested in engaging in the school's game of he-said, she-said. The bottom line is that it would have been simple for the principal to be receptive to discussing prior events and how to appropriately address Max's care in the future. If she were truly busy

preparing for an assembly scheduled to start 45 minutes after the Does arrived at the school, she could have set up an alternative time to talk to them instead of referring them to their attorney.[10]

Lack of trust

In your letter you claim to distill the underlying causes of these events as twofold—the parents are "upset that the District has not agreed to provide their specific training by their specific trainers" and their attorneys have "needlessly inflamed[d] the situation further." To the contrary, it is clear that you and your clients are gravely underestimating this situation. This is not a case of disgruntled or unhappy parents. In fact, we let the school attempt to do its own training. It is only when experience demonstrated that training had failed that we were forced to demand a better one. As stated by the school, the Does' "# 1 concern is Max's safety." ("Identifying Referring Concerns Document," Ex. I.) As for the Doe's counsel, our only agenda is to ensure that Max is provided with a safe and non-discriminatory education.[11]

At this point, the Does understandably do not trust the school. To even argue that giving Max insulin when his BG level was 71 without a fast acting glucose source is appropriate or attempting to assert that 428 is not dangerously high exemplifies why they do not trust the school and fear for their son's health and safety when he is there without the school nurse.

Sequence of District Personnel

The principal, Ms. Anderson, is not qualified to provide diabetes related care for Max.

- She is too busy with her responsibilities, be they assemblies, disciplinary matters, IEP meetings, administrative matters, or whatever other excuses she has proffered. It is entirely unacceptable that several serious incidents of concern were explained away by saying that she was "about to" take action or respond in some way.

- She has repeatedly made mistakes while caring for Max as well as exhibited serious misunderstandings about even basic facts about diabetes as a disease and about Max's care. She has tried to cover up these mistakes by passing on responsibility to a young child, indicating that he "bolused himself" or accusing him of lying. Her actions have exhibited a flagrant disregard for Max's safety and health.

- She antagonizes the parents and has repeatedly demonstrated inadequate conflict resolution skills. She has repeatedly refused to follow the DIHP directive to

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[10] At no point does the school deny that the special education coordinator has failed to return calls placed to her in a timely manner.

[11] Your suggestion that I am inflaming the situation rings hollow. Accusing the parents of "disruptive" behavior, when that alleged behavior is completely irrelevant to these discussions, as well as bringing up past events I did not even raise certainly seeks to fan flames, not douse them.

consult with parents about Max's care. Instead, in every situation, she has immediately referred the parents to "document your concerns and refer them to your attorneys." She has told the parents that things will "continue at this climate as long as your children are in this district."

- Nothing, not even under her alleged version of events, or viewed from the school's so-called "perspective," reassures the parents or Max that she is an appropriate person to provide his care.

Additionally, the school secretary is not qualified to provide care for Max. She admits that she is not comfortable with the administration of insulin, thereby demonstrating the lack of appropriate training provided to her. We have no reason to believe that she has been trained in the emergency use of glucagon, or that she would otherwise know how to respond in an emergency.

504 Meeting

The parents have already attended multiple 504 meetings on Max's behalf. The first meeting I attended was five months ago, in November. The school then called another meeting which did not occur until January, halfway through the school year. Since that time, we have continued to have problems, many of which we have dealt with in a forward looking manner or "let go" in order to focus on making the situation better down the road. (For example, because the majority of the time Max was not testing in the classroom or being allowed to record his own numbers, the parents provided the school with a log to record where the testing occurred and who did it, and all of a sudden the situation was resolved.)

Yet, based on the response in your April 1 letter which does not raise one suggestion to remedy these problems, we fail to see what could be accomplished by an additional meeting. Here is a sure fire way to end these problems:

1. Someone must be on the premises at all times who has been properly trained by a qualified diabetes educator or other expert about the care of a child with diabetes, who has been trained in insulin administration and the use of the insulin pump, and has been trained in the emergency administration of glucagon.

2. Someone besides the principal must be identified as the back up person to the full time nurse. In your January 30 letter you stated that the decision of who to train is left to school, "as long as the personnel assigned are qualified." The principal is not qualified. If the school wants to provide a nurse for Max whenever he is at school, that's fine with us. Or, the school can properly train lay persons in the school.

3. Better training needs to be provided to Max's caregivers. The principal's inability to interpret and execute the DIHP, the secretary's contention that she is not trained or

comfortable administering insulin, and the numerous violations of the DIHP and 504 plan prove that the training provided was not adequate. It has been the parents' position, from the beginning, that diabetes care does not require a medical professional, but appropriate training by a competent person is necessary.

4. The school must amend its plan to provide for an appropriate response to a medical emergency involving Max. The plan needs to include a specific sequence of steps, as delineated by the DIHP, and someone trained in administration of glucagon must be on premises at all times. The administration and staff must be trained on how to respond appropriately in an emergency.

The parents have conducted themselves reasonably and decently at all times. Your request that the parents conduct themselves "dispassionately" when advocating for their child is insensitive, at best. The Does have been providing care for Max since he was first diagnosed with diabetes at the age of 18 months. Since then, Max has required specific, life dependent diabetic care 24 hours per day, seven days a week that can not be suspended during the school day. Max is one of the 3% of children with type 1 diabetes who suffers from inexplicable "episodes" of grand mal seizures and unconsciousness which is why it is even more crucial that his care be appropriate and not taken lightly. Diabetes is not addressed or remedied with exact specifications, but requires constant adjustments based on experience and individualized metabolic responses. Max's health and safety depend on the school recognizing this and taking this situation seriously. Playing semantic games is a dangerous business.

Due to these circumstances, the Does are not comfortable having Max attend school unless the school nurse, Susan Johnson, is on site. Max loves school and he is very academically successful, but he is fearful that he will "die at school" if the nurse is not present. Since school resumed after spring break he will not get out of the car and enter the school unless the parents call to confirm that the school nurse is on site. You said that Max does not have to choose between attending school and his health, but that is exactly the situation the school has put him in.

Because litigation is always a last resort in disputes such as this one, we are willing to wait a reasonable amount of time for a response from your client prior to filing anything in court. Having said that, if we do not receive a response by Friday, April 16, 2007, we will assume that your client is unwilling to take the actions we have requested and proceed accordingly.

Sincerely,

Julie Burger, J.D.

cc: Mr. and Mrs. Doe