

October 10, 2004 – November 4, 2004
Shepherd Center Day Program

October 10, 2004

Hello everyone, I don't know where to start! Its been a whirlwind few days. I'll try to remember it all. We are now at the apartments provided by Shepherd for their Day Program patients. Internet connections are not set up, so I will be typing the updates in Word, then do a cut and paste into e-mail. So if things don't look quite right, like punctuation, that could be why.

OK, Friday we moved in. We had a carload of stuff; thank goodness Darren could take the bus over! I didn't have any room in the car for him, nor would I have been able to get him in and out myself. But I got all the stuff in, at least. Then we walked/pushed up a pretty big hill to get to Mick's Restaurant, where another patient was having a birthday dinner. We wanted to be on our schedule, so we ate dinner a little earlier than the party, then just joined them for a few minutes conversation. Back down the hill (VERY carefully since its now dark AND steep) and to the apartment to wait for Arianne, Michele and Medora. They arrived around 10. Ari went to see Paul, a Shepherd patient, who was leaving for home Saturday morning. We visited a while then started the night time routine. It wasn't too bad; we just took our time. The sleeping routine is going to take some getting used to. Only short amounts of time in between care.

Saturday we went to the Botanical Gardens, which is only a short distance away. It was a little overcast, but nice enough to be outside. The gardens were very nice, with a lot of glass sculptures by Chihuly. We really had a good time. The car transfers were tough, but do-able, especially with all of us helping. It was especially tiring for Darren, but he is getting stronger and able to help more. It was work for all of us, too! That night we got take-out for dinner, and just hung out at the apartment. We got started on the night routine, which included a shower, and I think it all took about 2 and a half hours. It went well, and we didn't have any problems, but I was so physically and emotionally drained., that once Darren was all set in bed, I just sat and cried. He hug me and rubbed my back, with us both agreeing that we had done a good job and it would get easier. Michele and Medora consoled me, while Ari went in by Darren. There were lots of hugs, tears and tissues. The night routines went smoothly, just not much sleep.

Today, we headed to the mall for a late lunch and some strolling/rolling around. We ate at a very nice outdoor restaurant, just enjoying the food and the company. It is just so good to be out of the hospital and doing "normal" things. Back to the apartment, to get our visitors back to the airport. We all realized how much planning and attention to details are needed for any kind of excursion. It was all worth it, though, and we got lots of good practice with car transfers. At one point, (was it the transfers or the shoulder massages?) that Darren said "you guys are all staying for 2 weeks, right?! Wow, wouldn't that be nice!!! Well, its good to progress to the next step, but this is going to be hard. All I have to keep thinking is "this WILL get easier/better" because I know it will. As long as I get afternoon naps, that is! One final thought: when I packed and moved, it became very evident how much STUFF we have accumulated! I don't mean this in a negative way, but please don't send any more packages, food, gifts, etc. Whatever gets sent, we have to get home! If there is anything you'd like us to have, please wait for us to get back to Kinnelon. It will just be so much easier! I know you'll understand.

With love, hope and prayers, Cynthia

October 12, 2004

Hi everyone,

I have a quick few minutes to write an update from the Library while Darren is in therapy. Everyone had Darren starting in the Day Program on Monday except the person who schedules the therapists. So, yesterday and today are sort of "transition days" where they have scheduled a few things to keep him busy and allow me to rest. Yesterday, while we wasted quite a bit of time waiting for a Doctor's order to have a kidney ultrasound (already a frustrating experience), I received a phone call saying Darren would not be starting in the Day Program til Wednesday. I said "that can't be" and went to that office when the ultrasound was finally finished, 2 and a half hours later. On top of this, I had been very unhappy with Darren's loaner wheelchair from the vendor, and was trying to reach the sales rep. Needless to say, when I was pleading our case for the Day Program to start TODAY, and not having enough sleep to begin with, I lost my composure and broke down. It was just too much all at once. So we worked out a compromise, and today was a much better day. He had a few hours of "therapy" with a technician yesterday, a session at the gym this morning, and another few hours this afternoon, including time on a "rickshaw" exercise machine. So all is not lost. And the vendor is coming this afternoon with a different loaner chair. So we'll see how that goes. As they say "tomorrow is another day" and that was certainly true to get through yesterday to today. And I look forward to that being true tomorrow, and the next day, and the next day after that, etc. We are trying to get a routine of having dinner, relaxing, bathing, personal care, and sleeping. I know it will get easier, but the short, interrupted periods of sleep are what's going to be tough. I may not need a lot of sleep, but I do like it to be in one stretch! That's not possible right now, so naps are in order. And I soon as I finish this, I'll be heading back to the apartment to do just that. In the meantime, we are both doing our best, and acknowledging each other's efforts. It feels like Darren has reached a plateau, but from what everyone tells me, I will see a lot of change in the Day Program. Darren is ready to work hard, as usual, so I'm sure there will be progress in the next 2 weeks. Then it will be time to come home, and we'll be ready! Boy, will we be ready!!! As soon as I know what the timeframe is, I'll be letting everyone know.

Please continue to keep us in your prayers, Cynthia

October 13, 2004

Hi everyone, I am SO HAPPY to report a bit of good news today – Darren's right tricep, which has been non-existent until now, is "firing." YEA!!! He always had a bit in his left, which has gotten stronger, and now that he has a bit in his right, they can start stimulating it and making it stronger, too. That is SUCH good news. We were happy with the Day Program OT evaluation today when the therapist found that, and had me look at it to see for myself. Darren was very surprised (pleasantly) but also disbelieving. "Where did that come from?" he asked. Well, things change, the therapist said, and today you have a right tricep. I got worried at lunch when another patient said that some days he has a tricep and other days he doesn't, but hey, at least it's there! Now they'll get to work on it. After a days worth of evaluations and meetings, the therapy team thinks Darren would benefit from 6-8 weeks in Day Program. But I know insurance is going to be pretty stubborn about giving us more than 2 weeks, and I'm ready to fight for a third, but after that, we want to get home and go to Kessler for more. They think Darren has "a lot of potential." I agree, and if we didn't have Kessler at home, I might be willing to reconsider, but I am real sure we both want to get home for a variety of reasons, especially to get our family back together. Well,

we are figuring out this routine, and I look forward to the weekend when John will be here to help. That will be so good. And I've rented a wheelchair accessible van so we can get around and do things, too. It will be a lot easier than making transfers, although that went well with all the help we had! (Thanks to Ari, Michele and Medora!!!) And we were able to get out and go places! Thanks for all of your support, and keep us in your prayers – obviously they're working!!!

Love Cynthia

October 14, 2004

Hi everyone, just a quick update today. Trying to get back to the apartment to straighten up, do laundry (you can't imagine how much laundry there is to do!), and rest. I am anxiously waiting for John to arrive later today. Not much news to report today, except for some about another patient. Mike broke his C6 on July 4th, and was a near drowning. He had a rough time, needed a trach, but is now looking pretty good. Darren told me this morning that Mike said last night his toes moved!!! Plural, too! That is such good news for him, and an indication that yes, things do happen slowly, but they do happen. I told Darren he would be next, that he MUST keep believing, and he will get more back. We were both smiling at the thought..... Darren looks so good today. Maybe because he spent the morning busy without me (OT and used the NuStep in the gym) while I rested and made phone calls, then he had a Doctor appt (the kidney ultrasound is all normal, thank goodness) and we had lunch together. Then I watched him go on the elevator to the 3rd floor therapy gym, and I came to the Library to check phone messages and e-mails. So he is on his own for the afternoon, (more OT and PT) and so am I. As most of you know, I don't have Internet access like I did, but I do read all my e-mails, as always. Please keep the encouraging and supportive words coming - each e-mail is very special - and I treasure your words. When you all ask me "what can I do?" - that's the answer. Even a short message that lets me know you're thinking of us keeps me going through the day.

I've rented a wheelchair accessible van this weekend, so I expect to be "out and about" even more than last weekend! Darren is really looking forward to this, and a visit from Ralph and Lucille, too, on Sunday. I'll write when I can, and thank you for keeping us in your thoughts and prayers.

Love Cynthia

October 15 & 16, 2004

Hi everyone, I am writing this Saturday night, while Darren and John are watching the Yankee game. Yesterday, Darren had a half day of therapy which included counseling, time in the gym and some PT. The counselor covered some material with him that he had missed in a key class, in the gym he did some cardio exercises on the Vita-Glide and went in the standing frame. He only got up to about 45 degrees, but the therapist encouraged him to stick with it, and in a few tries, he should be able to stand up. Then back upstairs for some PT, where he was learning to do more of the transfer himself, including placing the board under himself, doing the transfer and putting the board back in his backpack. Pretty hard stuff! He also sat up on the edge of the mat, with assistance from behind, and had to throw punches like a boxer. His therapists kept encouraging him to throw more and harder, and he was really trying. Since we rented a van for the weekend, we went to the paint store to try to help Darren pick a color for his new room at home. Then back to the apartment for a rest, before heading out to dinner. John remembered a place he had been before, and it turned out great. We had a really nice dinner. Today, we slept in before tackling a shower this morning. Then we went to the mall and to a movie. It's just so good to be together; I wish Ari were here to make us "complete." We all look forward to that soon. We also scoped out a place today to go and watch the Jets Game tomorrow. It's accessible and has lots of TV's. Should be fun. I hope Ralph and Lucille are up for that! We look forward to their visit. It has really been good to have John here, for obvious reasons. And of course, he hasn't lost his touch for doing laundry and washing dishes, so that has been a huge help! He's getting more comfortable in helping with Darren's care, and is enjoying being with us instead of being separated. Well, I will probably write again on Monday. I hope you all have a good weekend, and keep us in your thoughts and prayers.

Love Cynthia

October 17, 18 & 19, 2004

Hi everyone, no you didn't miss an update, there just wasn't any time to write! These last few days have been very busy! First, was Sunday, when Ralph and Lucille Rathynen visited. It was so VERY good to see them, and for them to see Darren as well. We sat and visited for awhile, before heading out to a sports bar that we had scoped out the day before to make sure it would be accessible. We had a really good time, just being out with friends, watching the Jets (and no we didn't force Darren to watch the Jets; he's really a big fan!), and all the other games, too, and eating. It was a beautiful day, the bar doors were opened, so fresh air came through. It was a good way to spend a Sunday afternoon. We went back to the apartment afterward, just sat and talked for awhile before we ate (again) some Chinese take-out. It was great having visitors, and seeing Ralph and Lucille. For all of us! Monday was what I consider Darren's first full day in the Day Program. He started out with OT, getting e-stim on his triceps, learning to button and un-button a shirt, take off his sweatshirt and other daily tasks. Then he worked on the "rickshaw" machine, lifting weights with his shoulders and triceps. After lunch, it was more e-stim on the triceps, then off to the gym for more exercises. Then the therapists (4 of them!) came to the apartment with us to do "life skills." On the way over, Darren was expected to do a lot of the pushing of his manual chair himself, including slowing it down while coming downhill. Then he pushed most of the way into the parking lot to our unit. He was pretty tired after that, and training hadn't even started! With his OTs, Polly and Becky, Darren shaved part of his beard using shave cream and a regular razor, and it was quite a lot of work. But he managed. Then into the bed, rolling over to lay prone (on his stomach) - which is a goal for sleeping because he could sleep longer in that position than any other. But its pretty difficult in a twin bed that feels even smaller, with only one railing that works. I'm hoping to be able to do this with him, but kind of scared.

The PTs, Christy and Quinn, were teaching us how to make a sliding board transfer onto a shower chair - also difficult. It took several tries, and I still don't feel confident to do that on my own. Then a shower, another transfer back into the bed, and they left. Now its about 6:30pm, we hadn't eaten, an IC needed to be done, and the wheelchair vendor was coming at 7 with a loaner chair. The vendor actually arrived at 7:15, and was there til 9:15. Almost everything on the loaner chair he brought had to be changed, added, adjusted, etc. They really paid attention to all of the details, but it took a long time. While they were there I made grilled cheese sandwiches for dinner...When they finished, I got Darren into bed, and an hour later I went to bed, totally exhausted. I did sleep well, to say the least! This morning, I had a brief meeting about our stay here, and we decided to ask insurance for 5 more days of Day Program. As much as we both want to come home, the program here is so good, we know it would be beneficial to stay. We'll see what happens. By the time I was finished, Darren was down at the gym, using a Vita-Glide machine for an arm/cardio workout. A few minutes with him down there, then time to go back upstairs for OT. They were going to work more on lower body dressing, since that is really hard for him, and he needs more practice. After that, he'll have "endurance pushing" - I don't know what that is exactly, but I'm guessing its pushing his chair, would should be interesting now that he has (another) new chair as of last night! Then pool time this afternoon and PT after that. So it will be another full day!

Now you see why I didn't have time to write before this!

Darren has been feeling some "pain" in two of his right toes, and the therapist encouraged me to stretch them often, and have Darren try to move them. They don't really hurt, he says, but feel "funny," possibly because there's more sensation there now than has been in the past. If anything new happens, I'll be sure to tell everyone!

Well, up to see how Darren is doing with his dressing. I'll write more when I can!

With love, prayers and hope, Cynthia

October 21, 2004

Hi everyone, I can't remember when I wrote last, so I hope I remember everything I want to say!!! If I remember correctly, Darren was doing an "endurance push" in his manual wheelchair the last time I wrote. Well, that involved pushing forward AND backward up the parking garage ramps! He said it was hard - DUH!!! - but he did his best. He really liked the fact he could do some of it backwards. Very tough, I'm sure. I can't remember all his therapy sessions, but they work him long and hard. He did a beak the other day with some pool time, but his session was cut short by thunder. I never heard of an indoor pool being shut down for thunder, but that's the rules. He was disappointed, but was still happy he got in for a bit.

Today he played wheelchair rugby as part of sports group therapy, and he said he had a much easier time of it this time, than last. I reminded him that's how he needs to look at things - not necessarily one day at a time. This encouragement was needed because I sensed a fair amount of frustration just before lunch when his OT was helping him with doing his own IC (intermittent catheterization to empty the bladder). He was having a hard time, harder than yesterday, actually, and seemed down on himself. After lunch, he went on the "rickshaw" machine and wanted to lift 10 pounds on each side, when previously he had been doing 7 and a half. Always trying to do more, always willing to push himself. That's what's going

to help him..... Well, I've been on the computer for awhile now, catching up, and now I'm getting kicked off. Sorry, I would have written more if I had more time. Keep your e-mails coming, I read them as often as I can....and keep your prayers and support,

Love Cynthia

October 22, 2004

Hello everyone, what a difference a few hours make! This morning, I was tired, cranky and worried about how we would manage the rest of our stay. I was worried that Darren would not be getting the full benefit of this Day Program, and that we would be going home while our house was still a mess. After some discussion, we (John, Darren and I) decided that even if insurance wouldn't cover the cost of another 5 days, we would pay for it ourselves. We think the program is well worth it, and it would give everyone at home that much more time to get things ready. Not that they're not working like crazy already; I know they are, and we are very grateful for that. But time helps, too. Well, just before leaving Shepherd at 1pm today, I received an e-mail from the insurance case manager that they will cover the Day Program through November 5th! So that means 7 additional days of therapy (when I was hoping for 5) which gives us 2 more full weeks, Monday to Friday. We are SO happy! I know it will be harder on me, and hard to be separated for that much longer, but in the long run, it is the best thing for Darren. So now, I feel like we have a definite plan, a workable one, and a good one. I feel so much better! Now, for an update on D-man, as Dr. Murray calls him occasionally.

His therapy group had a treasure/scavenger hunt this morning, going all around the hospital in search of various things. I didn't get too much detail, as usual, but he did tell me about trying to buy a soda from a vending machine. He could almost get the coins into the machine, but not quite. When he got help with that, and the can came down, he said there was no way to get the can out! This is what they call "problem solving" and in this case, it meant asking for help. We had lunch with Spencer, a young man who is in a wheelchair with an injury similar to Darren's. He's a former patient, and helps out with peer support. He might have another job at Shepherd, since he's always around, but I'm not sure. Anyway, he and Darren were sharing stories about how to do things – open a tube of toothpaste, pour milk, etc. – and it was good to hear Darren having ideas of his own. Spencer is a great role model, and Darren appreciated having time with him. Since Friday's are only half days of therapy, Darren came back to the apartment and took a nice nap. He's leaning on some pillows on the "countertop" in the kitchen. Quite an unorthodox way to nap, but he's comfortable. I'm going to see if he's up for going outside. One direction out of the complex is all uphill, but the other way is pretty flat. Maybe we'll head in that direction for some fresh air. I have some plans to get out this weekend, maybe taking the bus. As long as the weather is nice, that should be an option. I'll let you know....

With love and prayers, and hope that we'll all have a good weekend, Cynthia

October 26, 2004

Hi everyone, another busy few days here in Atlanta. I'll try to back-track and remember everything! On Saturday, we took the bus, regular public transportation, to ESPN Zone and back. Every bus on the weekends has a lift, and the drivers were courteous and helpful. It was so easy! We had a nice lunch, played some games - air hockey, bubble hockey and pinball - then had dessert and headed back. Darren was able to get around the place very well, but most all of the games have their own seats for driving/playing the games. So there wasn't much he could do, but we did what we could and enjoyed ourselves. Sunday we got some help to transfer Darren into the Kramer's car, and off we went to their house. We had a WONDERFUL day there, visiting, eating and watching football. It was just so good to be in a house! And their home is beautiful - warm and inviting. The company was great, and we just relaxed and enjoyed the day. More angels in our lives..... Yesterday, Monday, was a busy day of therapy. Since the therapists know now they have Darren for 10 more days, they have a plan for working him HARD! And he was tired. His PT kept teasing him that the insurance contract he had to sign said "there will be no rest" - does that give you an idea of their mind-set?! He's working so hard on doing a sliding-board transfer by himself. As I watch him, I pray for more muscle return and strength so he can transfer himself without that darn board. I get so jealous when I see these other people practically pop themselves from one surface to another, and Darren is working so hard (and usually with help, too.) More strength will help this process greatly. In the meantime, what he's doing helps improve his strength, as well as all the other activities he does in the normal course of the day.

I also set up his E-stim unit for his triceps early in the day, then later did his laterals (I think) while he lay prone (on his stomach). Laying on his stomach is really good because it gets him off his butt completely and stretches out his hips at the same time. Its tricky getting him on and off his stomach, but its worth it. Hopefully he'll get used to it, because if he can sleep that way during the night, he doesn't have to be turned that often. Last night, Darren wanted to participate in the rugby practice, so I pushed him back to Shepherd. I had hoped to borrow a van from one of the other families, but that didn't work out. And he thought it started at 8pm, but it really started at 7! Oh well, he did some laps around the gym, played in the scrimmage a little and did the "cool down." Not exactly what he wanted (the drills in the beginning are the best part for him), but it was good anyway. Then we pushed home..... Today is another busy day, but doesn't include me til the afternoon. So this morning I made phone calls, am catching up with all of you, and will meet Darren just before lunch. I am sorry not to be able to write daily. It is as helpful to me to write, as it is for to read, I think! And then I have to remember so much! But I do it when I can, and when I have the energy. I still enjoy keeping in touch, and I am able to read all of the incoming e-mails, so keep them coming! As we wind down these last two weeks, I feel that I need the encouragement and support now more than ever.

Thanks for keeping in touch! With love and prayers, Cynthia

October 28, 2004

Hi everyone, I have GOOD NEWS to brighten your day. Last night, Darren and I were watching a movie that we rented, when all of a sudden he said "look, Mom" and he was moving his right index finger!!! And he was moving it really well, too. He had me hold his wrist firm, so the wrist was not doing the work, and moved it quite a bit, just to be sure. We were both SO excited!!! Prayers are working, I am convinced of it. We have to keep the faith, and know that his healing is continuing. It may be slow, but it is happening. Yesterday, the whole group of Day Program patients went on an outing to a Farmers Market. Apparently, it was quite a large place, and Darren came home very tired from pushing around so much. They picked

out pumpkins and had lunch. After they ordered their lunch, the waitress told them all that a man who wanted to be anonymous, across the room offered to buy their lunches for them. What generosity! They were very touched, at least Darren was, to think a total stranger would do that. How nice of him to do such a good deed - that's a "mitzvah, right?!! I hope I got that right! Anyway, while Darren was out and about, I walked a long ways to do some shopping, have lunch and get a haircut. It did not seem like it was going to be such a nice day, but by the afternoon, my sweater was off and I was very warm. Some of the other moms don't understand why I don't ask for a ride or borrow their cars, but I just like to walk! It feels so good, and was such a nice day after all. We rented Man of Fire last night, and watched in on the laptop. Small, but so much better than our TV - poor quality and 4 channels....just that it was so long, and we got started on the evening care a bit late, getting to bed even later. I'm already thinking about a nap for later. But it was fun; we even made popcorn! We are very excited that John and Ari will be here tonight for 3 days. I've rented a van again for the weekend, so we will be able to get out and go places. Should be fun to be all together! And Darren's manual wheelchair is supposed to come at noon tomorrow (Friday) and he is excited about that. So am I, as I expect him to be more comfortable and independent in his won chair that's fitted to him properly. I'll let you know.....

With love, hope and prayers (keep them coming!!!), Cynthia

October 30, 2004

Hi everyone, a lot to write about, once again. John and Ari arrived here safely, even though their flight was considerably delayed due to bad weather in Atlanta. But they were able to meet up with us for dinner, where we were meeting Doug Charles and Trip (George) Winnie. It was wonderful to see both of them. Doug was the KHS football player who sustained a similar injury to Darren's and is fully recovered, and Trip is the friend from home who introduced us to him. Anyway, it was a really nice dinner, and great to have both of them around. Friday had all of the Day Program patients either painting pumpkins for Halloween or making cookies. As soon as John has time to upload the new pictures, you'll see their handiwork. It was quite a scene, and they seemed to all have fun. After lunch, the vendor came with Darren's manual wheelchair. I had such mixed emotions during this process. I was so happy that Darren was getting a wheelchair custom fit for him, yet I was so sad that he needed it. A tough situation. But staying focused on the present, as I have to sometimes force myself to do, helped me get through it. A few minor adjustments, but the right castor wasn't right and the chair was pulling to one side, so down to Seating Clinic we went. There, Darren had to get out of the chair, and the vendor worked on the chair some more. It seemed better, but once outside, Darren it a bump in the sidewalk, and the castor seemed to pop back out. Hopefully we can have it looked at on Monday. In the meantime, he is happy to be in his "own" chair, and I'm sure he'll be zipping around in no time. When I think of the progress he has made from his power chair to the first few times in the manual chair, til now, I am so impressed with his increase in strength. And its only getting better. Friday night, we just stayed in for a pasta dinner (pretty lame), played cards and watched TV. It was great to have John's help for the nightly routine, including a shower. It went much quicker! Today we had a wonderful day with one of the nurses, Charley, and his family. Charley spoke to us mid-week about having lunch together, but it turned out to be so much more than just lunch! Charley, his wife Beth and two sons, took us to Stone Mountain Park, where they brought a picnic lunch and all the "fixins." We had a nice time just sitting and talking, then took a tram ride up to the top of the mountain. It is the 2nd largest rock in the world, and has a carved sculpture, similar to Mount Rushmore. The view at the top was spectacular, even though it was hazy far off in the distance. The weather was warm and sunny, with a beautiful breeze. I could have stayed up there for hours! The tram and the building at the top were all accessible for Darren, but a little too bumpy out on the rock for him to

venture. As I stood at the edge, feeling the breeze and gazing into the distance, I prayed for the day when Darren would be able to walk to the edge himself and enjoy the scenery

. Oh, it seemed so unfair that he was not able to be out there. But as I looked out, I held the stone in my pocket that says "Faith" (I keep it with me all the time now) and said a little prayer that that could happen in the future.

It was such a special day, being in a beautiful place, with people who were strangers and now friends. It was so nice of them to take the day and spend it with us. More angels in our lives, and we are so thankful for them. We have decided that Ari will spend the week here, instead of going home Sunday and coming back on Thursday. It will be great to have her here, and a huge help in getting ready to go home and making the trip. In the meantime, we will be heading out for Monday Night Football to watch the Jets vs Miami. And Darren will be working hard this last week of therapy to be as ready as possible for his homecoming. The stronger he is, the easier it will be for all of us. I am looking forward to seeing some of you when we return, and I'll keep in touch as best I can during the week.

With love, hope and prayers, Cynthia

November 3, 2004

Hi everyone, more good news today as Darren said "oh by the way, Mom, my middle finger IS moving." Just like that. Of course, I say things like "really?" "let me see!" "move it again" and he moves it, ever so slightly, but its moving! There was some question when his index finger started moving last week that his middle finger was moving also, but it didn't look like it was moving by itself. But it really is. I really have to get with his OT to learn how to e-stim his fingers now, so we know before we go home. Maybe then they will go from just extending, to gripping. THAT would be wonderful! For now, we are thankful for any movement at all, since we believe that it represents more healing in the spinal cord.

AN IMPORTANT REQUEST: Does anyone local to Kinnelon have any kind of hospital bed for Darren to use until the one ordered for him comes in? A single or double would be great – the important thing is the mattress. Even if its not a bed, but a hospital/egg crate mattress would help. The only thing with that is I would need a twin or a queen, since that's the only size bed frames I have. Any specifics you can provide on the type of mattress/bed it is would be greatly appreciated. There is a chance I can get the vendor to provide one in the meantime, but I am very worried that it wouldn't get there in time. This was Darren's idea, to put it in the update, since it reaches so many people. IF you can help, please call me at 201-396-7603. If I don't answer, please leave me a message regarding what you might have. Attention neighbors – I might need some help coordinating the delivery if someone has a bed for us to use. Remember, we come home Friday afternoon, so there's not much time. I wished I had known sooner this was the situation, but I only got the info this morning.

Now to catch up on what we've been doing. On Sunday, we went to tour the Coca Cola facility. A bit heavy on marketing and advertising, but a neat thing to do. I enjoyed hearing the story of how it all began, and seeing the advertising materials through the years. Tasting all the different flavors was fun, but a little sickening after awhile. But it was all accessible and easy for Darren to get around. After that, we drove to Centennial Olympic Park, strolled and rolled around a bit, enjoying the warm weather. I am going to miss the sun and warmth, but I am SO ready to come home!

Monday brought a full day of therapy, PLUS "life skills" at the apartment with all 4 therapists afterwards. But it was really worth it. Learning how to do the things we'll need to know when we get home is so helpful. Trying to figure out ways to do things, with professionals helping, gave me so much more confidence. We did transfers in and out of the shower chair, Darren doing some of his own personal care, and a shower. He is able to do so much more himself, which is a huge help. And it will get better, I know.

A short, one hour nap, then we got up and drove to ESPN Zone to watch the Jets! Crazy, huh?! But Darren really wanted to go, and once we were there, I was glad we did. We sat and watched the game on a HUGE screen, and enjoyed the game since they were winning! We stayed til almost the end of the 3rd quarter, then came home and watched a little more, but not to the end. That was just too late. But it was fun. Darren even wore his Jets jersey!

Today, we were all a bit tired (hmmmmmm.....) and the day was another busy one. More dressing and personal care for Darren in OT, and more training for me in PT, mostly with the shower chair (again). It is so tricky, that the more I can practice here, the better I'll feel about it. Of course, when we get home, things will not be perfect right away if the elevator isn't in and we can't use the new bathroom, but it won't be long. In the meantime, we'll adjust and make do. In between, Darren did exercises, proned on his stomach, talked to a person about vans and driving and got into a power chair that he'll use for an outing tomorrow. Unfortunately, it's supposed to rain, and a few of the 18yr olds are going to Georgia State University to see what its like to get around a campus. I hope the weather improves for them. Should be a good trip. Ari and I might head to the mall for a while when he's gone.

It's been great to have Arianne here. Besides her being a big help with Darren, laundry, cooking, etc., she's also learning how to do transfers with him, and seeing what he can do for himself. I'm sure John is a bit lonely being home by himself, but I am really enjoying her being here.

While it is so easy to be self-absorbed in what we're doing here, and it doesn't leave much energy for much else, I do realize that life goes on elsewhere. It is with both sadness and happiness that I pass along some news about others. I hope the people involved don't mind that I'm doing this, but with the e-mail list being so extensive, I think it's helpful to pass it along. We mourn the loss of my close friend Charlene Butera's mother, Winnie. She was a wonderful woman who will be missed by many people. Also, Joe Ragno's father passed away. I know this is a difficult time for them and their families, and I offer my sympathy. On a happy note, to those in our extended ski family, who might not otherwise know, John and Denise Vas, had a baby boy, Cole Joseph. John is one of the coaches of the Rattlers Ski Club, and has been a great inspiration to both Arianne and Darren. What great news! Congratulations to them! So, as Darren often says "life goes on." And indeed it does.

Well, enough for now. As much as Darren wants to watch the election results tonight, I think we're headed for an early night. At least I am!

Good night to all, with love and prayers,

Cynthia

November 4, 2004

Well, I can't resist this greeting, as it will be my last from Atlanta: Hey Y'All!

OK, I said it! After 13 weeks here in Atlanta (tomorrow will be 14 weeks since Darren's injury, I think), it is a common phrase I hear, but don't use. It will always have a warm spot in my memory now. Now on the with the news. I am getting very anxious about our trip home. I keep thinking about all of the details and how they will all work out. This morning was the first morning in all of my time here that I overslept! It was only by 15 minutes, thank goodness, so I could make up the time and still have Darren ready for the bus.

As we spend our last full day here, I am thinking of all the things I am thankful for. We have met so many wonderful people, from the nurses and technicians to the therapists and the aides, to clerks and support staff. It truly is like a family here at Shepherd. We got a taste of true southern hospitality, both in and out of Shepherd. Making new friends and renewing old friendships has been a meaningful part of our time here. Since we are so far away from home, this has become our home, and the people here our family. But how excited I am to get home to NJ and our real family and friends. I can't believe its tomorrow! Today is going to be a very busy day. Darren already had OT, but much of the time was spent testing for discharge. The same will happen in PT this afternoon. But in between, he has sports group, where he's hoping they'll do rugby, then after lunch will try the standing frame before proning and e-stim. During all this, I have to speak with nursing, get prescriptions and supplies, and meet with the case manager to prepare for discharge. Its great having Ari here so she can be with Darren while I run around. Well, I hope to stay in touch via more e-mail updates when we arrive home, but they will probably be more inconsistent. I'll do my best. Please be patient with us as we figure out a schedule and a routine, and please always call if you do want to see us. Showing up on our doorstep unannounced could be awkward and uncomfortable. I want to avoid that, even though I know your intentions are well meaning. In time, we will get to see everyone, I promise! Phone calls and cards are welcome, and I hope we do all keep in touch as we make the transition home. Thank you in advance to all who have offered dinners; that is such a huge help! I can't thank you all enough for the support and encouragement you have offered these last several months. I couldn't have done it without you, and want you to know that YOU all have been a part of the coping and healing process. Thank you most for the prayers, as I truly believe in their power. May the prayers and healing continue.

Love Cynthia