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getting the word out

rj711

📅 Sep 8 2006, 05:14 PM [Email this entry](#) | [Print this entry](#)

hi from nyc...well tomorrow is the tape interview with abc action news on people who leave the country for stem cell therapy...it'll take place in my apartment which will make me feel less nervous...i firmly believe in this therapy and hope i can be an articulate advocate for fostering change here in the usa and raising consciousness about it...i'll post any info i get about when/where it will air...i don't have too much more to report at this time...i am working with another ot now once a week in addition to the wonderful guy i have at the outpatient clinic...my intention is to maximize the therapy at this particular time...i've switched acupunc-turists...i'm now seeing a chinese doctor who is an expert in stroke rehab...my usual guy helped me tremendously in the beginning but he changed for some reason and started to become shockingly negative about my recovery...i've got less than zero tolerance for that so god bless him but he's never going to see me again... 😊...amazing how we are guided to the next greater good...i'm over and out for now...have a good weekend!...richxxx

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labor day weekend

rj711

📅 Sep 1 2006, 06:57 PM [Email this entry](#) | [Print this entry](#)

hi...stem cell rich here with another update!...i am amazed and grateful that the dorsiflexion return to my left foot has remained and strengthened!...my pt guy is really thrilled as 2 weeks ago when we first started there was no movement

« April 2007 »

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tdehaas on [progress report/subluxated](#)

at all!...he suggested that i ask my rehab doctor to order a new, simpler afo that will factor in this new development!...ive graduated from my trusty quad cane to a regular cane...that quad cane served me very well but i must admit i'm so glad to be able to safely use a regular one now...as far as ot goes, my biceps and triceps are firing now!...i did have some movement prior to the cell therapy but now they seem to be strengthening...i don't want to put the cart before the horse but we think trace movements are showing up in my wrist now!...i'll keep posting... next saturday i'm going to be interviewed on tape by abc action news...linda hurtado is doing a story on people who leave the country to have stem cell treatments and what kind of results they are getting...i'm happy to be a part of this as the awareness of this promising therapy needs to get out to everyone...this is the therapy that will bring recovery to the devastation that a stroke incurs as well as to other degenerative conditions...with more research and trials the application of the treatment will improve and help more and more people who need it...nothing can stop scientific progress...this will prevail thank god!

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dorsiflexion returning! shoulder improving!

rj711

 Aug 25 2006, 05:05 PM [Email this entry](#) | [Print this entry](#)

hi all...i experienced the returning of the extensor hallucus muscle that raises the big toe on my left foot!...this was two days ago...in today's pt session it strengthened a bit (it's a smaller muscle) and there was also some firing of the peroneous muscle which raises the lateral part of the toes/foot!...my therapist was very happy for me as he clearly saw when we started two weeks ago that there was no movement whatsoever...this brought me back to kiev when several hours after the second cell injection i was able to flex my big toe for the first time since february...i'm so grateful for this return...it really gave me a boost as dorsiflexion is important to functional walking by regaining the ability to lift the foot of the advanced leg...i'm working hard in ot as well...the good news there is my shoulder range of motion and strength has increased!...my rotator cuff muscles have developed more tone (reducing the subluxation) and that pain in my left scapula isn't there anymore when i lie flat on my back...i'm more optimistic

that more returns are on the way now...stem cells + good old fashioned therapy seem to be working together for me!...i'll keep posting...best to all, richxxx

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more about the kiev clinic

rj711

 Aug 8 2006, 08:59 PM [Email this entry](#) | [Print this entry](#)

greetings...as i've already stated, i was very disappointed that i couldn't blog daily from kiev...so now i want to share more about the clinic experience for those of you who might be apprehensive about a ukrainian facility soooooo far from home...i viewed it all as part of an adventure (travel is my passion) but it wasn't until the car was turning onto the clinic block that i started second guessing what i was doing...i had a moment of doubt until i recognized the front of the clinic from pics that peter had shared with me...the building is beautifully designed...everything...and i mean everything in the clinic is brand new...it's a v.i.p. medical spa...the bedrooms are spacious and the beds are large and firm...private bathrooms are modern and meticulously clean...there are call buttons next to the beds to signal a nurse for assistance if necessary 24/7...the staff is prepared to physically assist patients in any way they need it...the nurses were terrific with any sticks that were needed for blood tests...helpful and genuinely pleasant...best and most importantly of all the doctors were all experienced with stem cell research and application...they have been treating people in this clinic for 20 years...the head medical doctor (working in the field for 25 years) answered all of my questions...i was left with a feeling of reassurance that these were the experts in this area...i received massage therapy just about every day along with e-stim and acupuncture...also my friend and i received facials with placenta cell masks by a cosmetologist...the most important thing for me was the professional competent way in which my entire treatment there was handled...i also toured the facility where the cells are harvested and stored...very impressive to see how this is run to insure no contamination...i can truly recommend the ict clinic based on my experience there...i look forward to returning there early next year!


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improved walking!...and possible malpractice... rj711

 Aug 7 2006, 05:27 PM [Email this entry](#) | [Print this entry](#)

hi guys...wanted to share about the huge smile on my face last night and why it was there:

my friend/part time caretaker andre came over last night and we decided to see the film 'the night listener'...i loved every frame of it btw altho it may be a bit too dark for some...we had just enough time to get there before it started...i was amazed at how easeful my walking was...i was safely taking longer strides!

it was honestly the first time i sensed the feeling of functional walking the way it was prior to my stroke...i had the small based quad cane but the feeling of increased speed and safely keeping up with andre was wonderful!...i went to bed last night happy and grateful......i saw a new neurologist this afternoon that i liked...way grateful for this too...she's setting up my outpatient ot and pt and will try to get me more acupuncture which is now offered free to rehab patients of the hospital...i'm usually apprehensive prior to seeing a new medical doctor...this visit went very well...

on another note i wonder if anyone has any feedback on this issue...i was not given the tpa shot in the emergency room even tho i got there 1/2 hour after my ischemic stroke...i did not lose consciousness...i was communicating and functioning cognitively and had no prior history of ulcers or bleeds of any kind...i can not help but wonder why that shot wasn't at least discussed with me as an option...i'm 51 years old for god's sake...i've contacted a malpractice attorney who took info and will get back to me...does this scenario ring a bell for any caretakers or survivors??...best to all, richxxx

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late wednesday night rj711

 Aug 3 2006, 02:16 AM [Email this entry](#) | [Print this entry](#)

greetings from greenwich village...i wanted to blog tonight especially now that my jet lag seems to be over...

update news: i have noticed a marked improvement in my emotional well being...my overall anxiety level is virtually

down to zero...this truly feels like heaven to me as i went thru a very dark period a few months ago where i honestly did not want to live this way anymore...i now feel an overall sense of well being...optimistic and happy...god it's a huge blessing just to genuinely use the word 'happy' again!!!!...😊...it's also a physical feeling of well being throughout my body...my thoughts are more focused on the positive...i took a big step today in making an appointment to start outpatient hand (ot) therapy at the hospital where i stayed initially after my stroke...i am thrilled that the specific therapist i requested is available...i had to end my home therapy when i went down to florida for the o2 therapy then directly after that i got the final nod to go over to kiev...so now it's time to get out of my apartment and do some WORK to get the returns i want in my left arm and hand...i also feel ready willing and able to restart my pt to strengthen/improve my walking...i've got 20 million stem cells as a new support partner now in all my endeavors...the doctors in kiev assured me that these cells will work for months and months to come...i'm expecting them to effectively assist me with more returns...i'll keep posting any and all progress...best to all, richxxx

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back in nyc!

rj711

 Jul 30 2006, 06:45 PM [Email this entry](#) | [Print this entry](#)

hi all...i regret very very much not having had any access to the net while i was in kiev...sorry...i just got home an hour ago and i'm pretty tired but had to get some words out to my strokenet peers!...okay...some bottom line stuff: it was a fantastic experience!...the clinic is state-of-the-art new...i thankfully learned a lot more about stem cells and how they can help stroke survivors from doctors who have been working in the field for 25 years...it's still incredibly confusing for me to understand it all...(plus there were communication problems re language at times)...more is being revealed as research continues...(over there at least!)...the entire staff was competent, professional and compassionate...i and my companion were truly taken good care of...my first dose of 10,000,000 placenta cord stem cells was introduced thru an iv on wednesday...it was a short procedure...20 or 30 minutes max...the prior 2 days were spent being examined and tested...nothing invasive or unpleasant...

the next dose of the same amount/type of cells was given in four im injections on friday...one in each triceps area and then one each in my right and left buttocks...later that day my left toes moved for the first time since february!...what an amazing feeling!...my stroke affected my left side...i walk with a quad cane quite well but thusfar i have not had any dorsiflexion or plantarflexion return...and no movement whatsoever in my toes...what i was told was to expect these stem cells to work on repair for up to 8 months....the doctors told me that often results can take 3 or 4 months...research has shown that these cells can penetrate the scar tissue that often surround damaged tissue...in my case, i had a heart attack in '94 which has weakened my ventricular contractions and covered them with some scar tissue in the damaged area...these cells can actually improve my heart function...i'm hopeful for this as the clot that gave me the stroke could have originated in my heart as blood tends to pool in someone with my condition before the ventricles contract...the same concept applies with these cells going to damaged areas of the brain...the cells pass the blood brain barrier to do this...i'm less clear on the mechanism of repair with the 4 im injections but they obviously worked to restore movement in my toes...overall i believe that this treatment will restore a lot of health and functioning...to what degree will remain to be seen...i'd love to report amazing returns to my left hand which is largely flaccid except for some flexion in my fingers...and hopefully i will in the near future...but i do know that i've received the most exciting and promising procedure that's available to stroke survivors...now what's next is to get my butt to good old fashioned pt and ot...believe it or not my discharge instructions are in russian...sheesh...luckily a good friend who was born and raised in russia is coming over tonight to translate for me...they strongly recommend pt and ot following this treatment...there are also dietary guidelines...they want me to be in touch with them so they can monitor my recovery and evaluate the need for more treatment in the future...probably in march/april '07...i was thrilled with kiev and discovering a new and fascinating country to explore...i'm crashing...i'll keep posting anything new...i'd be glad to answer any questions whatsoever...best, richxxx

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 today's the day!

rj711

☐ Jul 23 2006, 10:51 AM [Email this entry](#) | [Print this entry](#)

goodmorning...i slept well last night knowing that my clothes were all packed...i'm a notoriously late packer... this way feels so much better...everything else can wait a week until i return...the car is coming at 3pm to take sally and i to jfk...we'll arrive there 3 hours before the aerosvit nonstop flight is scheduled to leave at 6:55pm...i want to get there early to request seats on the emergency exit row...they have more legroom (i'm 6'3") which will make sleeping at least a possibility...staff from the institute of cell therapy will meet us at 11:10am with a wheelchair and handle getting us thru customs quickly...we'll go right to the clinic which is not far outside the city in a burb...sally will have her own room in the same building i'll be in so we can share meals together and hang out in between my treatments...a companion can also request to stay in a nearby hotel at no cost...i will spend the first day being examined by the ukrainian doctors...lots of ultrasound tests...bloodwork...neurological exam...they mustbe certain by their own standards that my current health jives with all the medical records i submitted...on one hand it's kind of a pain in the ass but really i'm grateful that they are this thorough to ascertain that i am tumor-free, infection- free, etc so that these cells can be safely and effectively administered for my optimal benefit...i do not smoke or drink alcohol...these are huge no no's...they will not proceed with the treatment if a patient is unwilling to cease and desist in these two areas...after my exam, the doctors come up with a dose/treatment protocol for me which begins the following day, tuesday...i consented to let them videotape me throughout the treatment protocol...getting out information about this therapy to survivors who have no idea what it is and that it's available is important to me... i look forward to blogging when i'm over there!!!!...i'd like to feel connected to my peers!...thank you for rooting me on in this exciting therapeutic endeavor!...bye for now, richxxx

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☐ **wednesday**

rj711

☐ Jul 20 2006, 03:28 AM [Email this entry](#) | [Print this entry](#)

greetings...i flew back to new york this afternoon...btw jetblue treated me wonderfully...a skycap met me with a wheelchair at the curbside check-in...i got my boarding

pass there then he took me thru security..beep
 beep beep...and right to my gate...the flight attendants were
 just as helpful...they changed my seat to the first row...the
 whole experience of flying alone was virtually anxiety
 free...well except for using the bathroom during some
 turbulence...😄...i went over to my bank to make the wire
 transfer to sceti...ouch!...lol...truthfully tho i'd choose to
 spend my very last dollar on this treatment...it's a whole lot
 of dollars for sure...the fact is that this stroke has
 devastated me...and another fact is that i can easily live for
 another 30 years...it seems to me that i can't afford NOT to
 spend all this money for as much return as i can possibly
 get back...now to jump to the o2 therapy...no amazing
 returns occurred in 18 treatments however i do know that i
 benefitted from this therapy...i'm the expert and authority
 on how my body is functioning...i have noticed subtle
 improvements...subtle is real...one example is that i swear i
 almost extended my fingers a couple of times in the past
 week...certain turning movements seem to have improved
 also...i believe in the science behind hyperbaric o2 therapy
 for stroke survivors and i would have definately stayed for
 more treatments but my stem cells are waiting for me in
 kiev...i may well return to orlando for more hbot after the
 cells are introduced...it's also time for me to get to out
 patient pt and ot to do some more varied work/exercises...i
 stopped my homecare pt and ot when i left for orlando...i
 intend to find a ndt trained ot to keep bringing back my left
 arm/hand/fingers...and i need to be pushed again in pt
 doing more exercises to keep improving my walking...i was
 glad to hear that therapy is provided in the kiev clinic...wow
 i'm pooped after a long day...over and out for now...😄

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more info from peter

rj711

 Jul 17 2006, 04:20 PM [Email this entry](#) | [Print this entry](#)

greetings...i met with peter sidorenko yesterday for 3 1/2
 hours...he provided a lot more background info about his
 company and the relationship that they have to the clinic in
 kiev and why they chose them...i'm now about as
 comfortable as i can be with this entire endeavor knowing
 more about how it operates...my understanding of what to
 expect has been deepened...
 i've learned that there are many important aspects to this
 therapy: the techniques the clinic uses to cryogenically

store the cells and then how they 'defreeze' them for optimal viability...the kiev clinic holds a patent on the solution they have deveoped which contains the cells prior to injection...scti has a 10 year contract with kiev...and they use fetal stem cells which scti feels are the most effective...many other off-shore clinics use stem cells from the placenta cord blood only...he assured me of the strict testing that is done at several points along the way to insure that every dose is completely uncontaminated...(viral-free, bacteria-free)...he also gave me a head's up on the cultural aspects/attitudes i may encounter in and out of the clinic...i found peter to be completely communicative regarding all aspects of this therapy...i did get more info regarding the sub-dural injection to my current satisfaction...peter himself is going for the same therapy in august...i feel ready to fly over there sunday with less anxiety and more excitement to see how this treatment can help me...i'll blog as much as i can when i'm there...best, richxxx

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