

Spinal Cord Injury SIG

Spring/ Summer 2014



Letter from the Chair

Welcome to our Spring/Summer 2014 Newsletter!



KJ Hutchinson
SCI SIG Chair

Our annual PT Conference is happening as I write this letter. If you were lucky enough to be in Charlotte, NC, I hope that you caught the Mary McMillan Lecture and the Oxford Debates, they were not to be missed!

It is that time of year that we have to say goodbye to our outgoing SIG members. **Lauren McCullough, PT, DPT**, our Nominating Committee Chair member, is rotating off her position after three years in service. Thanks for your support, Lauren! Please welcome **Rachel Tappen, PT, MPT** our newly elected member of the nominating committee. You will hear more about Rachel in our Fall newsletter. I am also happy to note that I have been re-elected to continue to serve as the Chair of our great SCI SIG! We have a lot of great ideas that will help us to continue to improve our SCI Care and our SIG in general. I look forward to helping to implement many of those ideas in the coming months/years. Many thanks to all who ran for positions.

Please let me also take this opportunity to thank our many CSM 2014 speakers for their SCI SIG-Sponsored presentations in Las Vegas, Nevada this past February. **Laura Cohen, PT, PhD, ATP/SMS, Allison Fracchia PT, ATP/SMS** and **Twala Maresh PT, DPT, NCS, ATP** presented on the use of assistive technology to promote healthy aging in persons with SCI. Many thanks, also, go out to **Andrea Behrman, PT, PhD** for assembling an “All Star” cast presenting their work on locomotor training following SCI. Thanks to fellow presenters **Michele Basso, PT, EdD, Marcie Kern, PT, MS, Sandra**

Wojciehowski, PT, DPT, March Schmidt Read, PT, DPT, MS, Gail Forrest, PhD and **Jeffery Buehner, PT, DPT, MS** for taking time to share your expertise with our members! Both of these presentations were filled to capacity and highly regarded educational sessions! Handouts for these and all CSM 2014 sessions will only be available through early June.

We hope you like the new organization or our SIG webpages. Our Nominating Committee has reorganized the content, so it is now easy to find resources geared to Clients, PTs or families. If you haven't been on the site in the past month or two it is worth taking a look. (<http://www.neuropt.org/special-interest-groups/spinal-cord-injury/resources>)

In our past newsletters, we most recently focused on bowel/bladder and male sexual function after SCI (<http://neuropt.org/special-interest-groups/spinal-cord-injury/newsletters>). These joint efforts were supported by a variety of published literature and scientific expert reporting. In this newsletter, **Twala Maresh, PT, DPT, NCS, ATP** takes a look at unique PT considerations for pregnancy following SCI. She has ‘first person’ testimony of the process and suggestions for how PTs can better serve women with SCI to prepare or cope with pregnancy. See page 3 to start reading the details. And finally, in our Clinician’s Corner Section, we highlight **Laura Cohen’s, PT, PhD, ATP/SMS** efforts and discuss her passions/ motivations for all her PT advocacy work in the reimbursement arena. This is an often neglected area for involvement and critical for the health and well being of our SCI Clients.

Well, that is all for now. Enjoy!

Until next time...

Karen J. Hutchinson

SCI SIG Officers:

- Karen J. Hutchinson, Chair
- Meghan Joyce, Vice Chair
- Marcie Kern, Secretary
- Lauren McCollough, Nom. Com. Chair, Outgoing
- Erin Culverhouse, Chair Nominating Com.
- Twala Maresh, Nominating Com.
- Rachel Tappen, Nominating Com.

Inside this issue:

| | |
|---|-------|
| Letter from the Chair | 1 |
| Reproduction issues in Women with SCI | 2 & 8 |
| Survey of Females with SCI/D | 3-6 |
| New Neurology Section SIG | 7 |
| CSM 2014 Speakers | 7 |
| Clinician’s Corner— <i>Laura Cohen</i> | 7-8 |
| Resources for Reproductive Health and Pregnancy for | 8 |
| Future Courses | 8 |

Reproductive Issues in Women with Spinal Cord Injuries

A review of the literature

Twala Maresh, PT, DPT, NCS, ATP and Lindsay Terry, SPT

The majority of spinal cord injuries occur during young adult years.¹ Sexual function is often impaired post spinal cord injury, (SCI) due to damage affecting motor, sensory, and autonomic functioning. Rehabilitation professionals need to have an understanding of the role that sexuality and reproduction plays in the lives of their client. They have a responsibility to listen to the client's concerns with enough knowledge to answer questions or to direct them appropriately so that their questions can be answered. The ultimate goal of rehabilitation is to offer guidance and instruction to help clients live satisfying lives.^{4,5} A study by Alexander et al, in 2009, reported that the number one priority of recovery of the participants with paraplegia was improved sexual function. The participants with tetraplegia had the same priority second only to regaining arm and hand function.² The study used the Female Sexual Function Index (FSFI) instrument to assess an individual's sexuality and sexual response after SCI. This is a self-report instrument with questions related to desire, subjective arousal, lubrication, orgasm, sexual satisfaction and pain, in order to assess the participants sexual responses. The FSFI was found to be a reliable tool for females with SCI.²

Clinicians are often at the mercy of busy schedules with limited ability to discuss in depth, the more sensitive topics of sexual or reproductive functioning with their clients. Herson and colleagues published a study, in 1999, that discussed barriers clinicians may have when obtaining sexual information from clients. As previously mentioned, having too little time was a major concern for the clinicians who participated in the study, as well as a perception that it was not their job to be the one to initiate the conversation with their client. Lack of knowledge about sexuality for this population along with lack of readiness on the client's part were also barriers discussed. It is important for clinicians to provide a comfortable atmosphere for the client and their partner to discuss sexuality information and offer options for referral if more appropriate information can be provided by another professional.^{3,16}

Women who became pregnant after SCI were twice as likely to experience preterm labor and birth as those who became pregnant before having a SCI.

Camune BD. (2013). Challenges in the Management of the Pregnant Women with SCI. *J Perinat Neonat Nurs.* 27 (3): 225-231. <http://www.ncbi.nlm.nih.gov/pubmed/23899801>

A study by Beiring-Sorensen et al, in 2012, examined sexual function in women at least ten years post SCI. Of the participants, 22% of the women had given birth post injury and 69% reported being satisfied with their sex lives. The women that stated they were satisfied were statistically found to be younger and were injured at a younger age than the women who reported that they were unsatisfied with their sex lives.⁴ The dissatisfaction was correlated to bladder and bowel management, pressure ulcers, spasticity or pain.⁴ Another study by Kreuter et al, in 2011, was congruent with these findings, stating that negative changes in the participants sex lives were attributed to decreased or lost sensation, bowel and bladder problems, and difficulty

in positioning due to spasticity or pain. The women also reported psychological changes such as feeling unattractive, having less self-confidence, and difficulties finding a partner.^{8,9}

A woman's fertility is generally not compromised by spinal cord injury. In most cases, a woman is as fertile following the accident as she was before accident.

Maria Reyes, MD, Assistant Professor of Rehabilitation Medicine, University of Washington

This research shows that rehabilitation is not solely physical, and that the patient's emotional and mental state should be addressed as well.

Pregnancy in women with SCI is a topic that has been researched in the past and continues to be a topic of concern regarding risks, family dynamics, and the changes women go through during pregnancy. Researching the topic and talking to other mothers with SCIs are two ways women are making the decision on whether or not they want to experience pregnancy.^{1,5} Studies have shown that women with SCI, that have been pregnant and had children, felt they were treated different clinically. The women stated specifically treatment was different in terms of the care they received, their freedom of choice and environment. The women stated that it was important to them to have support and feel empowered as any mother should.^{6,7} Women must also consider the physical changes that occur during pregnancy and how these changes will affect their life with a SCI. Complications during pregnancy, noted by multiple studies, included frequent autonomic dysreflexia, pressure ulcers, increased spasticity as well as increased difficulty with bladder care, decreased ability to transfer and propel a wheelchair.^{13,14,16} Spasticity was found to interfere with 26% of SCI women, and especially effects those women with incomplete injuries.¹⁵ Pregnancy impacts the lower urinary tract in neurologically intact women, therefore, women with SCI that are pregnant are considered a high risk population for UTIs^{10, 11,12,13,16} Women with SCI, who are pregnant, are in a high-risk category of developing pressure sores due to weight gained and postural changes.¹³ *(All of these areas are within the domain of physical therapy and should be assessed and treated by the PT.)*

Researchers recommend that a physical evaluation by a therapist be considered to ensure the needed changes are made in seating and assistive devices. The therapist should be able to suggest proper modifications to the patient's pressure relief patterns, cushion and or wheelchair to decrease pressure sore risk.^{13,15} Research has shown that pregnant women with SCI can also benefit from deep breathing exercises, chest physical therapy, and intermittent positive pressure breathing to prevent respiratory complications.¹⁵

Further research is needed to address Physical Therapy education guidelines, client access, funding and utilization of physical therapy services for women with SCI who are pregnant or considering pregnancy.

References on page 8

{See page 3– 6 for a survey of females with SCI and pregnancy.}

Survey of Females with SCI/D on Reproductive Health and Experience



Erin Gildner and beautiful baby boy

Erin Gildner and
Twala Maresh, PT, DPT, NCS, ATP

A survey was sent to a Social Media group made up exclusively of females with SCI asking for information on reproductive health and their experiences during pregnancy. The participants were informed that the information would be used to assist in the education of Physical Therapists and all agreed that the findings could be presented in the SCI SIG newsletter. A total of 8 participants responded. All of the participants had children post SCI or were currently pregnant. Basic demographic information included age, years SCI, and number of years post SCI for first child. Ages at injury or diagnosis ranged from birth to 31 years with a median age of 19.9 years. Number of years post injury ranged from 5 to 40 years with a median of 16.6 years. Six of the participants reported that they were incomplete (5 AIS B and 1 AIS C) and 2 were complete injuries. Functional levels ranged from C 6 to L1 with 5 at the paraplegia level and 3 at the tetraplegia level. The number of years post injury before their first child ranged from 0 to 10 years with a median of 7.6 years. The number of children delivered post injury, ranged from 2 participants currently pregnant to three births. One participant reported having twins (one girl and one boy) however the female child died 3 days after birth.

The following are additional questions and responses with *PT CENTRIC INFORMATION IN ITALICS*:

1. During pregnancy, what has been your experience with finding a knowledgeable physician?

- Excellent
- My Maternal Fetal Medicine doctor knows and deals with SCI frequently.
- Terrible. First pregnancy was horrible because I was young and hadn't even been injured two years at that point. I didn't have good insurance so I received care from Residents and didn't know at that point that most don't understand SCI. With twins, and one with a congenital birth defect, I should have been labeled high risk and should have received care from a more experienced MD at that point, but I didn't. I went into labor 15 weeks early and they didn't even check my cervix when I went into the hospital; by the time anyone thought to check it, it was too late and my son's head was already crowning. It was a traumatic and awful experience. The second pregnancy was a little better because I went to high risk, but still didn't feel like I had a truly SCI knowledgeable physician.

- Luckily my doctor had experience with treplegia and twins.
- I have found that in my area, it is rare to find someone who is knowledgeable about SCI, much less about SCI and women's health. I am very fortunate that I have a great OBGYN that was willing and eager to do research and learn all she could about my condition and how it affects women's health and pregnancy. She has been great.
- I was sent to a high risk pregnancy center in Cincinnati, OH. It was easy for me to find.
- I've been lucky. My local OB/GYN didn't have tons of experience. But he has been willing and eager to do the research and talk to any doctors who could help him be come more informed. He's been open minded and extremely helpful and comforting.
- Not difficult I found that most physicians were very open with what they felt they could handle and because I do not have dysreflexia I think it may have been easier for me to find a great OBGYN

2. What were the barriers you faced in accessing offices of healthcare providers during your pregnancy?

- Because I had Medicaid and was not employed at the time of both my pregnancies, I received, in my opinion, sub-par care. I also felt less than because I would be stared at strangely in the office waiting rooms. Most of the offices that I received care in didn't have accessible exam tables; luckily my husband was able to come with me to most of my appointments and transfer me. I also didn't get weighed because there was not an accessible scale in any of the offices I went to. My last pregnancy I was actually asked to go weigh myself at my Physical Medicine and Rehab Doc's office, which was out of the way and a major inconvenience. There was a lack of staff training on transfers. There was a lack of physical accessibility training and things would always have to be moved during my visit to get into the bathroom to give a urine sample, get into the exam rooms, etc.
- None just the (*body weight*) scale :)
- The two biggest barriers were the exam tables and insurance. *The office did not have adjustable exam tables, so I had to transfer to a pretty high table. It is difficult but doable when I'm not pregnant, but when I was lifting 20-30 extra pounds and was off balance because of my large stomach, it made it almost impossible.* I had to have help every time. Also, the office had never dealt with Medicare based insurance for a pregnancy case. My insurance is through Blue Cross but it is still a Medicare plan. Even the insurance company didn't know what to do. They finally had to just make a decision about what they would pay since they had never had to pay out for a pregnancy. It was a long process trying to get it worked out. *To be honest, the office was more accessible than the hospital where both of my girls were born. The rooms were small and the bath rooms were horrible for pregnant individuals with SCI.*

Continued on pg. 4

About half of all women who have experienced a spinal cord injury never miss a period as a result of the accident. The other 50 percent experience a disruption in their menstrual cycles that usually lasts anywhere from three to six months. In most cases, the monthly menstrual cycle returns with no lasting effect on fertility. *Maria Reyes, MD, Assistant Professor of Rehabilitation Medicine,*

2. What were the barriers you faced in accessing offices of healthcare providers during your pregnancy? Cont.

There was only one or two rooms where the bathroom was big enough for a wheelchair, and the way they were laid out made it very hard to get in and out of. I was able to have the same room for both of my deliveries. The toilets were very short and hard to transfer on and off of, especially while pregnant and after delivering a baby. The hospital didn't even have toilet benches that I could use over the toilet. My second daughter was born early and was in the NICU for 24 days so I stayed at the hospital the entire time. It was very frustrating to not have a bathroom that I could easily use.

- Physical - getting on and off the tables, weighing, etc.
- My OB/GYN's office doesn't have an accessible weight scale. My husband will accompany me to appointments and pick me up to weigh me. Or we will do the same at home the night before if he can't go to the appointment.
- Exam tables are of course an issue. Exams and ultra sounds definitely need to be done on days my husband can go with me. Or at times nurses or even my doctor has helped me up on the tables.
- None from the doctors office-- I have faced these issues in life and people questioned my getting pregnant however I did not feel the physicians or their associates treated me differently.

3. Did you seek advice from a PT during your pregnancy? And if not, why?

- No; no need.
- No, I just hadn't thought I needed to.
- No, not that I recall. I did have contact with my physical therapist during pregnancy but felt that I was capable of transferring and being mobile. I didn't even think about being able to benefit from seeing a PT; kind of wish I had.
- No. But would have been great for info on how to deal with baby. Had to figure out alone
- *I was seeing a PT for therapy at the time of both my pregnancies, but we never really discussed anything pregnancy related.*
- No, I did not. They did not want to start PT on me until I had the baby.
- Yes. I did so on the first pregnancy hoping for any tips on challenges I might not be expecting.
- *No! that's almost funny- what PT knows a thing about pregnancy and spinal cord injury? I have never met one and I have known many.*

4. Did your physician recommend seeing a PT during pregnancy for assistance with transfers, positioning in wheelchair, etc? If so, did your insurance provide coverage for the PT referral?

All participants reported that their physician did not refer them to PT during or prior to pregnancy. One participant responded that they wished that they had been referred and one reported that maybe the reason for no referral is that they had contact with a trusted PT, so he probably figured that I had it covered...

5. Do you think that a PT has the knowledge to assist with these issues?

One participant reported that "No, a PT does not have the knowledge to assist with these issues", two reported that, "Yes they do (*have the knowledge to assist*) and 5 reported that they had some knowledge or that they did not know their knowledge in this area.

6. What has been the most challenging aspect of pregnancy from a physical mobility standpoint?

- Ongoing morning sickness
- Gaining weight does change the way I transfer.
- *I think the hardest was learning how to transfer and learning where my center of gravity was. I also had to learn how to carry the additional weight and turn over from side to side at night. I was very thin before my first pregnancy and gained weight quickly with twins. I normally lean forward to transfer and I would almost top ple over by the 3rd month because I was about the size of a full-term single pregnancy. One time I lost my balance on a toilet transfer and had to be rescued by my neighbor; it was very embarrassing and I'm lucky I didn't hurt myself or anyone else.*
- Low blood pressure
- *I would say getting my wheelchair in and out of my vehicle. I drive an SUV so it is a little high off the ground. Bending over to get my chair was almost impossible once my belly got large. Also bending over to get things off the floor was difficult.*
- *The ever changing center of gravity and balance issues.*
- *It became more and more difficult to transfer smoothly as I got towards the end of the pregnancy.*
- *Loading my chair in my car became challenging as my belly got bigger too. "*
- *Sitting at the end of pregnancy is difficult and I experienced lower back pain I also had varying degrees of tightness and then toward the end you loosen up in preparation for birth. I would almost recommend massage as every bit as important as therapy when your pregnant and in a chair.*

7. Have you had any significant secondary complications during your pregnancy?

- Transverse breech C-section; 2nd baby too large had to have a C- section.
- UTI
- My first pregnancy I had severe bladder infections and it eventually led to a kidney infection where I had to be hospitalized at 20 weeks. I didn't have skin breakdown, but I did have trouble with constipation. My second pregnancy I developed severe hemorrhoids due to bowel changes and eventually had to have surgery.

Continued on page 5



At 4 months, Erin was already experiencing changes in her mobility, transfers and pressure/comfort in the wheelchair.

7. Have you had any significant secondary complications during your pregnancy? Cont.

- Multiple kidney infections. 4 each pregnancy.
- During my first pregnancy I had several UTI's and ended up in the hospital for a few days for a severe UTI. I didn't really have any issues with my second pregnancy except that my daughter was born premature at 34 weeks. We never really figured out what caused me to go into labor early.
- No.
- I had a few seizures after I got home with my first pregnancy. We determined it was due to AD. We think poor pain management was the cause for the AD. So the plan this time is to stay in the hospital a little longer and leave the epidural in a little longer as well.
- The major issue all three times was my bladder.... it changed during pregnancy always resumed once I was post... but I could not rely on the usual sensations I could sometimes not tell if my bladder was empty (I do not use a catheter) I did not get any infections and that was fortunate but I went to the bathroom much more often (obviously) and could not be certain if I had actually emptied.

8. What were your concerns about preparing for your child's birth?

- Giving birth and having my doctor present. He wrote a script and he was there!
- The pain afterwards and how we would manage it.
- I was concerned about not knowing when I would go into labor (which was a valid concern because on my first pregnancy I went into labor hours before I knew it. I just thought it was false contractions). I was also concerned that I would be all alone when I went into labor and wouldn't be able to transfer to the car and drive myself to the hospital.
- AD
- The first time around I was nervous about everything. I wondered how I would be able to push the baby out and I didn't want to have a c-section. I was worried about nerve pain during delivery since I have problems with it on a daily basis. (It was not a problem during delivery.) I was also concerned about bladder/bowel issues during delivery. With my second pregnancy, I wasn't as concerned about everything since I already knew what to expect and because my first delivery went very smoothly.
- Everything! How to deliver, how to care for myself, how to care for my baby, how to hold them and roll safely, how to get them in and out of bed, how to load them in the car.
- My main concern was my physical ability to care for a new born.
- I think caring for them was a concern here is where you must make the largest of sacrifices and compromises and perhaps it is difficult to envision being a mother with a disability, It was for me although that may not be every one's issue. Getting up at night when your tired, making the babies room work so you can grab what you need etc. I have not and did not find a way to accomplish these goals without help. My husband helped at night and whenever he could during the day.

With my first two I actually paid for help. With the third, we did it with the two of us and it was possible but very exhausting - all worth it of course!

9. Who was your support for education about SCI and pregnancy?

- Husband and family
- Husband, mother, Craig Hospital, friends, family
- "My spouse, family, friends, and the internet were my support.
- None
- I gained knowledge about pregnancy from my mom and other friends and family members. I also used my husband (a PTA) for knowledge about SCI and pregnancy. I read many articles and forums about pregnancy and SCI.
- Just my family.
- Other peers with spinal cord injuries who had been through pregnancies, family, friends, educated professionals.
- Quite honestly beside my amazing OBGYN I had no other support I just did it!

10. Educational Resources used?

- Research online
- Blogs, Facebook groups, articles
- "I did contact ""Through the Looking Glass"" and they helped a little, but not much. I got a lot of information from the Care Cure Community because I was able to talk to moms who had already experienced childbirth and parenting after SCI. [http:// sci.rutgers.edu/](http://sci.rutgers.edu/)
- I read "What to expect when you're expecting" along with many articles and forums on SCI and pregnant. I looked at many websites related to pregnancy.
- A friend that was introduced to me who was a paraplegic and had 3 natural births all post-SCI.

Continued on page 6

Pregnancy Surveillance for the Women with Spinal Cord Injury

Camune BD. (2013). Challenges in the Management of the Pregnant Women with SCI. *J Perinat Neonat Nurs.* 27 (3): 225-231. <http://www.ncbi.nlm.nih.gov/pubmed/23899801>

| Trimester 1 | Trimester 2 | Trimester 3 |
|---|---|--|
| AD triggers and symptoms UTI Nutrition Skin integrity Risk for DVT Depression/ anxiety Anemia Bowel motility Motor ability Miscarriage | AD triggers and symptoms UTI Weight Gain Pressure Sores DVT Depression/anxiety Anemia Constipation Motor stability Preterm Labor | AD triggers and symptoms UTI/pyelonephritis Weight Gain Pressure sores DVT Depression/anxiety Anemia Constipation Motor instability Preterm Labor |

11. Can you share any trade secrets to managing the secondary complications of SCI during pregnancy?

- Watching weight gained and breastfeeding to recovery
- Lots of water. It can help almost everything.
- I think that a prophylactic antibiotic and probiotics was helpful the second time around, but that's something to ask a physician about. I think getting exercise and being as active as possible helps with lots of issues, and hind sight being 20/20, I think that consulting with a PT would be helpful to learn how to manage your new pregnant body.
- B12 for nausea
- Strap attached to w/c for holding infant to chest / stomach
- Give you're body plenty of down time and rest. It is easy to get worn out during pregnancy. Especially when you are pregnant in a wheelchair. Also, urinate frequently. Bladder incontinence is a problem during pregnancy but I found that if I went every 1-2 hours it helped so much. That seems like a lot, but it also helps with UTI's to void frequently.
- Do what you are told! Rest, take your blood thinners for the length they say, wear those horrible hose and enjoy your baby! What a miracle!
- I think most people with SCI are in tune with their bodies and pregnancy is a time to be more in tune. Listen to your body sometimes it will misread but usually your instincts are correct - find a great OBGYN one that listens to the issues you are concerned about. advocate for yourself and address the issues up front explain what you think you need... maybe more visits than you might have had with no disability... I know they checked me out more often be cause of my SCI but I took comfort in the visits I was diligent about my weight gain and I made sure to try to do some exercise - for me it was a stationery bike. it's not easy - being pregnant with SCI but there are risks in every pregnancy and you need to go into it with strength of mind and an attitude that you will be proactive should some thing arise.

12. What advice would you give the PT to help educate their client before pregnancy from a physical, equipment, and/or home management point of view?

- *Connect with other moms*
- *None*
- *Know your resources and give them as much information as possible. This is a scary time and many women with SCI, especially with the first pregnancy, aren't always sure where to turn.*
- *Be encouraging, because it's often likely that many of the people in their life are not.*
- *If able to, it might be helpful to practice lifts and real life situations with an 8 lb medicine ball. Use exercises that they will be able to use in a real life situation. If you could meet them at a baby store with cribs, maybe see if the store would allow you to take an 8 lb. medicine ball to place in a crib (early in pregnancy, obviously) to see how they can maneuver and get it out.*
- *Borrow swings or other baby items that you can use in PT. The stronger and more confident they are before birth, the better.*
- *Please do your research and be proactive in finding information for them. Nothing is more bothersome than*

a PT or healthcare provider that doesn't take the time to learn about SCI and pregnancy, if they don't already know.

- *Cradle next to bed initially. Crib with easy access. Strap for chest hold.*
- *Getting in shape before pregnancy is a great thing to do. It helps so much with transfers and such. Make sure you have a wheelchair that is comfortable and that is light - weight and easy to push. Also, a standing frame, bracing or a standing wheelchair is a great thing to do during pregnancy. Standing always helped with the circulation and swelling in my legs and feet. It also felt great to stretch out and give the baby room to move.*
- *Help them through every stage. Pretend large belly transfers, set up a mock nursery with adapted baby items so they will know what to do at home and can practice before the baby comes. Teach good health and nutrition to help against too much weight gain during pregnancy. Weight gain is a whole new ballgame for fitting in your wheelchair AFTER baby comes.*
- *To keep an open mind and remember things may get tricky, but it's possible and completely doable.*
- *That is difficult, many therapists did not know any more about pregnancy and SCI than me. If I had questions, they would refer to a manual. Something I could easily do myself. I suppose they could address the transfer issues, comfort and spasticity maybe even bladder? But not the issues of pregnancy and are they qualified to do so? Is this part of their training? I am probably not the best at answering this question as I did not use my PT as a resource in any of my pregnancies.*

The participants in the this survey had very similar experiences as has been reported in the literature. It was very interesting to read their answers especially in regard to physical therapy use and knowledge. Question 12 outlines multiple "PT moments" for education, mobility assessment and treatment that may have benefited the client during pregnancy. Problem solving, by the PT, in functional mobility could be utilized without specific education in pregnancy and S SCI. The Physical Therapist has the responsibility to include basic education on reproductive issues with their client and or refer to the appropriate professional. Additional research is needed to determine the role of physical therapy in the reproductive health for females with SCI. Education and awareness is also needed for the unique skill set that physical therapists can offer regarding seating and mobility assessments, transfer training and skin-integrity issues.



Erin with her two handsome boys today.

SCI SIG CSM 2014 Speakers



L to R : Twala Maresh PT, DPT, NCS, ATP ;
Allison Fracchia PT, ATP/SMS and
Laura Cohen, PT, PhD, ATP/SMS,



L to R: Andrea Behrman, PT, PhD; Michele Basso, PT, EdD, Sandra
Wojciehowski, PT, DPT; Marcie Kern, PT, MS, , March Schmidt Read,
PT, DPT, MS, Jeffery Buehner, PT, DPT, MS and Gail Forrest, PhD

New Neurology Section Special Interest Group Assistive Technology/ Seating and Wheeled Mobility or AT/SWM

<http://www.neuropt.org/special-interest-groups/assistive-technology-seating-wheeled-mobility-sig>



Clinicians Corner featuring Laura Cohen, PT, PhD, ATP/SMS

Laura Cohen, PhD, PT, ATP/SMS is the Principal for Rehabilitation & Technology Consultants, LLC in Arlington, VA. She is the Executive Director of the Clinician Task Force a national group of seating and mobility clinicians working to influence Medicare and Medicaid coding, coverage, and payment policies for complex rehab and assistive technology devices. For the past 15 years she has provided second level review services for a third party payer reviewing DME requests in 21 states. As a Senior Clinical Consultant for the van Halem Group, LLC, Dr Cohen provides counsel, leadership, and clinical expertise to clients when it comes to medical necessity, benefit integrity, policy development and compliance. Dr. Cohen is the past Chair and ex-officio member of the RESNA Professional Standards Board, appointed to the editorial board for the journal Assistive Technology and RESNA Fellow. She works part time at MedStar National Rehabilitation Hospital providing direct patient care in the Seating and Mobility Clinic. Her research interest is to promote outcomes research designed to influence clinical practice and impact public policy. She was instrumental in developing the new Assistive Technology, Seating and Wheeled Mobility Special Interest Group in the Neurology Section and serves as the Vice Chair.

The following are questions and answers the SCI SIG asked Dr. Cohen regarding her career in Advocacy for Clients with SCI.

What were the major motivating factors that propelled you into a roll of advocacy?

I have a friend that refers to me as Don Quixote because of my passion for equality and justice. Early in my career, I was frequently told that what my client needed was either not covered or not available. Simply put I could not accept that response and set out to find out "why not?". What I learned was the key to accessing the technologies and services I was seeking on behalf of my clients was understanding the policy requirements and ensuring my documentation supported it.

When I encounter policies that block access I later learned to be an advocate at a State and Federal level working with agency decision makers and legislators. I learned I could be much more effective helping to change a broken system than fighting each case one by one into perpetuity! One person can make a difference, teaming together can make a bigger difference!

What is the number one misconception among PTs regarding Assistive Technology for persons with SCI?

Accepting that a person with SCI needs AT to achieve his/her highest level of function and independence is NOT giving up on his/her potential or goals to continue to progress. AT serves to level the playing field now.

Continued on page 8

Resources for Reproductive Health and Pregnancy in Females with SCI

- **Mother-to-Be: A Guide to Pregnancy and Birth for Women with Disabilities By:** Judith Rogers and Molleen Matsumura **Cost:** \$24.95 - **Date:** 1991 Demos Publishers, 386 Park Ave S New York, NY 10016. 800-532-8663
- **Through the Looking Glass** 2198 Sixth St, Suite 100, Berkeley, CA 94710-2204 800-644-2666 or 510-848-1112 or email: TLG@lookingglass.org **Web site:** <http://www.lookingglass.org> Provides clinical and supportive services, training and research to families in which one or more members - whether parent of child, has a disability or medical issue. Available from Through the Looking Glass - **Adaptive Parenting Equipment, Idea Book 1** Handbook of ideas for more than 40 pieces of adaptive equipment. \$10 to families / \$25 professionals.
- **Parenting with a Disability** Free newsletter to parents with disabilities & their family.
- The Sexuality for Women (http://www.christopherreeve.org/site/c.mtKZKgMWKwG/b.4453433/k.F255/Sexuality_for_Women.htm) includes basic information on female sexual function, and childbearing and childcare.
- <http://www.uab.edu/medicine/sci/uab-scims-information/reproductive-health-for-women-with-spinal-cord-injury-video-series>
- http://sci.washington.edu/info/forums/reports/women_sci.asp **SCI Forum Report**
- Mobilewomen.org : <http://carecure.rutgers.edu/mobilewomen>
- Pregnancy and Women with SCI (SCI InfoSheet #15). Spinal Cord Injury Information Network, University of Alabama at Birmingham (UAB) -Spain Rehabilitation Center, 1717 6th Ave. S, Birmingham, AL 35233; (205) 934-3283 .

References from page 2

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Clinician's Corner Cont. from page 7

What are PTs greatest weakness when it comes to documenting for reimbursement for assistive technology?

I find that most PTs do not know how to access payer coverage policies. These documents are equivalent to the "decoder ring" for successful funding for both services and technology. Referencing the source "Local Coverage Determination" for Medicare (or equivalent document for other payers) details eligibility criteria and documentation requirements so you know exactly what needs to be included – no guessing needed.

Is there one major goal that you would like to achieve, from an advocacy perspective, before you retire from PT?

I would like to see the value of PT widely recognized by the consumers of our services (clients, caregivers, families, payers and policy makers). PTs are the experts on mobility and function. We have the potential to help individuals achieve their highest level of mobility and function to live active and productive lives in their homes and communities. I would like to see our profession have the capacity to generate, aggregate and report empirical evidence of outcomes such as effectiveness, efficiency, satisfaction and cost so we can demonstrate our value to society and claim the position of the superstars we have the potential to be!

Thanks Laura for your willingness to contribute to the SCI SIG newsletter!

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