# Non-Invasive Surface Electrical Spinal Stimulation for Children with Spina Bifida

**Facebook:** @SpinalStimGerti / **Instagram:** @spinalstimgerti / **Email:** spinalstimulation@gmail.com

The spinal electrical stimulation program for Spina Bifida (SB) was developed in 2017 by Dr. Gad Alon PT, Ph.D. an internationally recognized researcher in electrical stimulation and Gerti Motavalli PT, MPT. It has been published in an online research journal, *Child Neurology Open*, in 2019. Several other articles and TV segments about spinal stimulation have been produced and links are attached. There are videos and information posted on Gerti's Facebook and Instagram page. Currently, Gerti has treated over 90 children with SB so far. She is also consulting



with many other PTs who are using her treatment protocol throughout the US, and many other countries around the world. She has developed an online course for practitioners to get trained in spinal stimulation.

# Who can benefit from spinal stimulation?

- Children with Spina Bifida. Gerti has treated and seen progress in children ages 3 months to 13 years. So far no upper age limit has been establised.
- Infants can begin as early as 3 months once their scar is healed.

# What are the Benefits of Spinal Stimulation?

Progress varies from child to child. Almost all children who have started spinal stim with Gerti Motavalli, PT have shown progress in at least one, but often several systems listed below. Most children show changes within 2-8 weeks and continue to change over months and years.

- Increased circulation, warmer feet, better healing of skin break down.
- Increased sensation all children get tested with electrical stimulation at the beginning of spinal stim for muscle response and sensation. This is an easy non-painful way to gain valuable information. At re-testing after 2 months of spinal stim, many show sensory or muscle response to lower electricity documenting new nerve growth. Children have reported to feeling parts of their body they were unaware of before.

- Increased movements, new muscles get activated, for example, ankle or toe
  movement never seen before appearing initially during spinal stimulation and later
  spontaneous outside of stimulation and hopefully eventually voluntary.
- **Increased strength** in weakened trunk and/or leg muscles, resulting, for example, in better walking
- Urinary continence a few kids have been able to gain bladder control, some have
  gotten off the need for catherization as recommended by their urologist. A protocol for a
  one-month continence trial has been developed with a pediatric urologist and can be
  shared with your child's urologist.
- Less constipation many parents of children who are not on a bowel program have reported less or no more constipation. Some children who had fecal smearing have developed the strength to hold their stool.

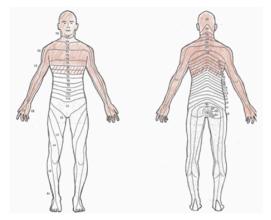
# What are the possible negative side-effects?

- With the right parameters there is no danger to the spinal cord.
- Dr. Alon wrote: Selected references of clinical studies since the early 1980s provide clear evidence that applying electrical stimulation to enhance the recovery of children with multiple diagnoses and ranging in age from 6 month to 18 years is safe. None of these studies reported any short or long-term adverse response of the neurological or musculo-skeletal systems. Exception is the known issue of possible skin irritation under the stimulating electrodes. Like any other intervention, there is always a need to screen each child to determine if she/he is a candidate and to rule out any adverse, undesired responses. (the long list of studies is in the addendum)
- Spinal electrical stimulation cannot be used if child has an implanted device, such as a pacemaker, VNS or baclofen pump
- For children that have a VP shunt that is adjusted with magnets, there's no specific study about the safety. According to Dr. Alon, it is very unlikely that spinal electrical stimulation would interfere with the magnet setting at all since the electrical stimulation unit itself has a very small magnetic field and is placed far away from where the VP shunt is placed. The electricity used for the stimulation does not interfere with the magnet.
- The intensity is at a level where there is no pain for the patient.
- The skin is checked frequently for tolerance, especially in babies and new patients. Should there be excessive redness or small blisters it should heal within a few days.

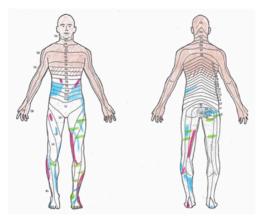
# What happens during spinal stimulation?

- Electrodes are placed over the spinal cord and on the bottom of the feet.
- The e-stim unit gives electrical impulses from the lower back to the legs, like nerves would do to activate muscles. The muscles will contract in response.
- The family is instructed in how to use the stimulation at home, initially 20 minutes and later up to 2x30 minutes daily.

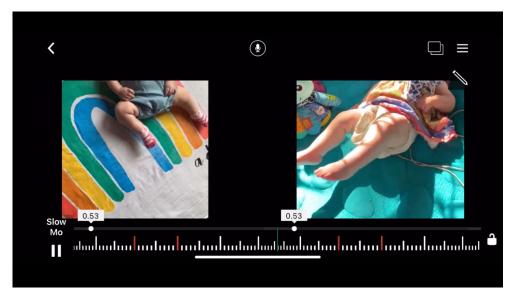
- During the spinal stimulation the child can sit, play or lie around and read books, watch TV, or stand in the stander.
- Parental supervision is needed but besides placing the electrodes and starting the unit there is no other work needed from the parent.



6-month-old child with T10 SB. No sensation below the ribcage.



1 year later with spinal electrical stimulation. Sensation present in different areas of legs and trunk.



Child with SB level L3/4 who started spinal electrical stimulation at 4 months. Her legs would only move into bending hips and knees. She had no hip extension. After 6 weeks of spinal electrical stimulation, she started extending her legs.

#### Where is the Therapy?

#### 1, In person with Gerti Motavalli PT at her clinic

#### Near Jacksonville Florida, close to a beautiful beach, 2 1/2 hours from Orlando

- 2-3 sessions over 1 to 2 days with Gerti for evaluating muscle function/sensation and setting up the child's spinal stimulation program.
- The family will be instructed in detail on how to implement the spinal stimulation program daily program at home. They will get written instructions of test results and therapy.
- The follow up of the established spinal stimulation program could be:
  - Through your therapist who can get trained in spinal stimulation (a free 4 hours online course in spinal stimulation will be offered to any therapist who supports a family that came to Florida to get started). Gerti can consult with your therapist if they have questions.
  - Through online sessions with Gerti <u>IF</u> the family is either in Missouri or Florida during the time of the appointment. You need to either live in one of those states where Gerti is licensed <u>OR</u> send me an e-mail and tell me when you will be visiting one of those states and we can set up an appointment.

Cost is \$275 for 2 sessions 2 hours \$ 370 for 3 sessions 3 hours

#### **Intensive therapy with Gerti**

- **3 days** 2 hours a day including spinal stimulation, functional electrical stimulation (stimulation muscles in function such as walking) and whole-body vibration therapy (influencing muscle strength, balance, and sensation).
- The family will be instructed in detail on how to implement the spinal stimulation program daily at home. They will get written instructions of test results and therapy.
- The follow up of the established spinal stimulation program could be:
  - Through your therapist who can get trained in spinal stimulation (a free 4 hours online course in spinal stimulation will be offered to any therapist who supports a family that came to Florida to get started). Gerti can consult with your therapist if they have questions.
  - Through online sessions with Gerti <u>IF</u> the family is either in Missouri or Florida during the time of the appointment. You need to either live in one of those states where Gerti is licensed <u>OR</u> send me an e-mail and tell me when you will be visiting one of those states and we can set up an appointment.

#### Cost is \$665

• **5 days** 2 hours a day including spinal stimulation, functional electrical stimulation (stimulation muscles in function such as walking) and whole-body vibration therapy

(influencing muscle strength, balance, and sensation). Aquatic therapy can be added based on the season.

- The family will be instructed in detail on how to implement the spinal stimulation program daily at home. They will get written instructions of test results and therapy.
- The follow up of the established spinal stimulation program could be:
  - Through your therapist who can get trained in spinal stimulation (a free 4 hours online course in spinal stimulation will be offered to any therapist who supports a family that came to Florida to get started). Gerti can consult with your therapist if they have questions.
  - Through online sessions with Gerti <u>IF</u> the family is either in Missouri or Florida during the time of the appointment. You need to either live in one of those states where Gerti is licensed <u>OR</u> send me an e-mail and tell me when you will be visiting one of those states and we can set up an appointment.

Cost is \$ 1,045

Due to licensing requirements, Gerti will not be able to follow up with you remotely (unless you are in Missouri or Florida at the time of the online session). Your options are

- 1, to come back to her clinic after 3-6 months
- 2, get your PT trained in spinal stimulation (Gerti will send her four hours recorded course in Spinal Stim (value \$250) to your physical therapist for \$30 registration fee after you travel to Florida to initiate treatment.
- 3, find a PT trained in spinal stimulation (there are not many at this time, Gerti can send you a list)
- 4, Gerti will request a liability waiver for all children seen remotely

#### 2, Remotely through Gerti Motavalli PT

For families in Florida and Missouri only

- Since Gerti is licensed as a PT in Florida and Missouri she can treat by teletherapy
- The family does not have to permanently live in Florida but needs to confirm with Gerti that they are physically in Florida at the time of the treatment.
- A session lasts 45 90 minutes
- The family will be instructed in how to set up the e-stim unit, what to observe/expect and how to use the treatment at home, initially 15 minutes e-stim and later up to 60 minutes daily.
- Coordination with the child's therapists is always encouraged and welcome.

Cost per session (45-60 min) is \$95. Initial session (60-90 min) is \$180.

Payment will be requested from you by PayPal after your appointment. A PayPal account is NOT required on your end.

# 3, Your PT/ OT/ DO/ MD/ Chiropractor gets trained in Spinal Stimulation

- Your practitioner does not need prior knowledge in electrical stimulation, Gerti will send all the information needed to start spinal stimulation. Once payment of \$250 has been received, Gerti will share
  - The recorded 4 hours webinar course about spinal electrical stimulation and functional electrical stimulation through a Zoom link
  - o The power point presentations used in the video recording.
  - Detailed written summary of introduction into electrical stimulation, testing the muscle-nerve connection and administering spinal stimulation
  - YouTube videos how to set up the e-stim unit for testing or therapy

Here is the link for the spinal stimulation course:

### Sign up for Webinar

https://hipaa.jotform.com/221653833983161

#### Not sure about starting?

Schedule a 30 min video conference with Gerti to discuss your questions and concerns. You will be asked to send 3 short videos of your child that Gerti will evaluate

Cost is \$50

#### What is Needed?

- Physician order for physical therapy to evaluate and treat can be faxed to 1-888-336-6337
- **E-Stim Unit**: The Chattanooga Continuum Kit (formerly EMPI Continuum) unit is strongly recommended for Spinal Stimulation because it has safety features that other units do not. When one electrode comes off the whole channel shuts down. Without this feature when one electrode comes off double the intensity of current will be in the remaining electrode.
  - This unit can be bought for about US\$ 420
  - Most companies will only sell it to professionals
  - Make sure you order the Chattanooga Continuum Kit. It comes with lead wires and a hand switch.

• <u>Electrodes:</u> Look for 1.25" round (baby) or 2x2" square or 2x3" (for abdominals and gluts/botton) electrodes. Look online or contact Healthy You (352) 369-4900 and mention my name Gerti Motavalli and you will get wholesale prices. Buy Superstim electrodes.

#### If you can't get the unit yourself, Gerti can send you

- the Chattanooga Continuum Set electrical stimulation for \$420
- Shipping in the US is \$17.
- You can add electrodes for \$50 per 10 pack (should last 3-5 months)

#### Here is the link to buy the e-stim unit and electrodes

https://form.jotform.com/212073943654154

# **Payment**

Within the US:

PayPal @Spinalstim



PAYPAL.ME

Pay Gerti Motavalli, LLC using PayPal.Me

Go to paypal.me/spinalstim and type in the amount. Since it's PayPal, it's easy and secure. Don't have a PayPal account? No worries.

Venmo, Zelle, check or cash

Gerti cannot bill your medical insurance. You can request an itemized bill to turn into your flexible spending account, submit to insurance or other possible reimbursement avenues.

Payments for the therapy will be collected after the therapy session. For people traveling to Florida the payment is due on the last day.

#### A little bit about Gerti Motavalli

Gerti Motavalli, PT, MPT grew up in Germany and got her initial physical therapy degree there in 1984. She has worked with children all her professional life, over 35 years now.

She worked in Germany, India and the United States. In 2000, she received her Master of Physical Therapy from the University of Missouri-Columbia. Gerti has her private pediatric practice and always strives to learn the most cutting-edge therapy. In 2005, she started using electrical stimulation with her patients and in 2017 she developed the spinal electrical protocol with Dr. Alon. In 2020, she was honored as one the most outstanding physical therapist in



Missouri by the American Physical Therapy association.

# **Testimonials:**

Impact on bladder pressure and walking

Our daughter is currently 5 years old and we have been doing spinal stim since June of 2020. In June 2021 we changed the focus of her spinal stim to focus to strengthen her glutes to help her with taking independent steps and to give her more strength through her hip area. After 1 week we saw huge improvements. Her strength to stand independently and take steps had improved significantly. 2.5 months had gone by and my daughter had started being vocal about having to go to the bathroom. This was something very new.

A majority of Spina Bifida kids have damage in the spinal cord that control their ability to use the toilet in a conventional way. Most can have what is classified as a hostile bladder. This is where the bladder has high pressures and contracts more then it should potentially causing reflux into the kidneys. The more your bladder contracts the thicker and less elastic it becomes which can be problematic as you grow and the bladder is supposed to hold more urine. Urodynamics or CMG or a bladder study is performed on these kids. My daughter has had this test since she was about 9 months old. Every 6 months we've had a repeat to see how her bladder is doing and it always trended towards a hostile reading meaning that her pressures increased and there was more risk to her kidneys. Interventions were made and in April of 2021 we were officially on Tethered Cord watch.

BUT..... remember when I said we changed our spinal stim protocol in June 2021 and that my daughter was more vocal about having to use the bathroom. When our Urodynamics came back unchanged I asked to give us some time with the new protocol with the spinal stim.

Our results in January of 2022 were outstanding. My daughter's results came back with no abnormal bladder pressures. She went from having pressures of 35 to 4. We did our spinal stim almost every day, I believe has created some connection to her bladder allowing it to relax and stay elastic. A pressure of 4 is a normal reading. This is truly amazing news!! Its really unheard to go from a hostile bladder to relaxed pressure free bladder.

I can't say enough about Gerti's protocol and her individualized plan for each child she sees. Not only has Gerti's protocol allowed my daughter to become stronger and more independent but has allowed her bladder to be safe. That in itself is worth trying something that is non invasive! As I always say every child is different and this is our experience but I would highly reach out to Gerti and give it a chance! I can't thank her enough.

Cassie Chicago USA

"Our 18-month-old son, born with myelomeningocele at T12/L1, has seen some amazing improvements in both movement and sensation since beginning the e-stim at 6 months of age. The movements he already had have gotten much stronger, and we have also seen movements in parts of his legs and feet that he didn't have before. Sensation has improved quite significantly as well, particularly on his "good" side, and he can feel temperature and touch all the way down to his toes. It's been exciting to watch, and we look forward to continuing with the treatment." ~Carolina & Pedro, Vancouver, Canada

"We have worked with Gerti using Spinal Stim with our son, Brody, since he was 6 months old, he is now 4 years. We were amazed when we started the process and have seen steady progress ever since. Brody is SB L5 but functionally T10. We use spinal stim to trigger muscles he cannot use on his own. We have seen an increase in sensation and spontaneous muscle movement outside of spinal stim. He has never had any adverse reaction to the stimulation." ~Ally and Taylor Moreland, Centralia MO, USA

"Our son Bradley is 7 years old and has Spina Bifida (myelomeningocele). His opening was at about L2-S3 and he had surgery in utero to repair his back. He is ambulatory but has lacked significant movement in his toes as well as his left foot. He has been working with Gerti since he was approximately 9 months old (both physical therapy and electrical stimulation of the muscles) and started spinal stimulation using the e-stim unit about 2 years ago. We have noticed a great increase in the sensation Bradley has in both feet, especially his left foot, which has really helped Bradley as he grows older to notice any irritations/sores with his feet much quicker. The therapy is very easy to use/set up and is easily fit into Bradley's normal routine". ~Ashley and Vic, Columbia MO USA

# **List of Resources**

Facebook: Spinal Stimulation Spina Bifida Gerti Motavalli

Instagram @spinalstimgerti (videos of spinal stim and progress children made)

#### Published Research Article about Gerti Motavalli's Spinal Stimulation:

Search: Child Neurology Open Sage Pub Electrical Stimulation https://journals.sagepub.com/doi/pdf/10.1177/2329048X19835656

The application of functional electrical stimulation and noninvasive spinal cord electrical stimulation (transcutaneous spinal cord stimulation) protocols to a 6-month old infant with myelomeningocele has not been previously reported in the medical literature. The observed gradual development of previously absent sensory and motor responses in this infant was novel, surprising, and encouraging. Functional electrical stimulation and spinal cord electrical stimulation are well tolerated and have minimal, transient adverse events when applied to infants with spina bifida. The initial positive outcomes and safety of the novel application of electrical stimulation for this case infant provide a basis for further research into a new intervention approach which could enhance development for infants born with spina bifida.

#### **Television News Articles:**

Search: Families share benefits of electrical stimulation therapy on children with Spina Bifida <a href="https://krcgtv.com/news/local/families-share-benefits-of-electrical-stimulation-therapy-on-children-with-spina-bifida">https://krcgtv.com/news/local/families-share-benefits-of-electrical-stimulation-therapy-on-children-with-spina-bifida</a>

#### Published articles about the use and safety of electrical stimulation with children

1. Samejima, S. Caskey, C. D. Inanici, F. **Multisite Transcutaneous Spinal Stimulation for Walking and Autonomic Recovery in Motor-Incomplete Tetraplegia**: A Single-Subject Design. Phys Ther 2022;102: DOI10.1093/ptj/pzab228.

CONCLUSION: These results suggest that noninvasive spinal cord stimulation might promote recovery of locomotor and autonomic functions beyond traditional gait training in people with chronic incomplete cervical SCI. IMPACT: Multisite transcutaneous spinal stimulation may induce neuroplasticity of the spinal networks and confer functional benefits following chronic cervical SCI.

- 2. Anastasia Keller1,2, Goutam Singh 1,2, et al. **Noninvasive spinal stimulation safely enables upright posture in children with spinal cord injury** NATURE COMMUNICATIONS | https://doi.org/10.1038/s41467-021-26026-z
- 3. Solopova IA, Sukhotina IA, Zhvansky DS, et al. **Effects of spinal cord stimulation on motor functions in children with cerebral palsy.** Neurosci Lett. 2017;639:192-198.
- Krucoff MO, Rahimpour S, Slutzky MW, Edgerton VR, Turner DA. Enhancing Nervous System Recovery through Neurobiologics, Neural Interface Training, and Neurorehabilitation. Front Neurosci. 2016;10:584.

- 5. Gerasimenko Y, Gad P, Sayenko D, et al. **Integration of sensory, spinal, and volitional descending inputs in regulation of human locomotion**. J Neurophysiol. 2016;116(1):98-105.
- 6. Lee NG, Andrews E, Rosoklija I, et al. **The effect of spinal cord level on sexual function** in the spina bifida population. J Pediatr Urol. 2015;11(3):142 e141-146.
- 7. Sayenko DG, Atkinson DA, Floyd TC, et al. **Effects of paired transcutaneous electrical stimulation delivered at single and dual sites over lumbosacral spinal cord**. Neurosci Lett. 2015;609:229-234.
- 8. Shideler, B.L., et al., Toward a hybrid exoskeleton for crouch gait in children with cerebral palsy: neuromuscular electrical stimulation for improved knee extension. J Neuroeng Rehabil, 2020. 17(1): p. 121.
- 9. Elnaggar, R.K., B.A. Alqahtani, and M.F. Elbanna, Functional outcomes of botulinum neurotoxin-A injection followed by reciprocal electrical stimulation in children with cerebral palsy: A randomized controlled trial. Restor Neurol Neurosci, 2020.
- 10. Salazar, A.P., et al., **Neuromuscular electrical stimulation to improve gross motor function in children with cerebral palsy: a meta-analysis**. Braz J Phys Ther, 2019. 23(5): p. 378-386.
- 11. Oshima, O., et al., Effects of hybrid assistive neuromuscular dynamic stimulation therapy for hemiparesis after pediatric stroke: a feasibility trial. Disabil Rehabil, 2019: p. 1-5.
- 12. Marcus, S., et al., **Neuromuscular electrical stimulation for treatment of dysphagia in infants and young children with neurological impairment**: a prospective pilot study. BMJ Paediatr Open, 2019. 3(1): p. e000382.
- 13. Magalhaes, P., et al., Is transcutaneous electrical muscle stimulation an alternative for preventing acquired muscle weakness in the pediatric intensive care unit? A scoping review. Pediatr Pulmonol, 2019. 54(8): p. 1108-1116.
- 14. Elnaggar, R.K. and M.F. Elbanna, Evaluation of independent versus integrated effects of reciprocal electrical stimulation and botulinum toxin-A on dynamic limits of postural stability and ankle kinematics in spastic diplegia: a single-blinded randomized trial. Eur J Phys Rehabil Med, 2019. 55(2): p. 241-249.
- 13. Andreoli, S.M., B.L. Wilson, and C. Swanson, **Neuromuscular electrical stimulation** improves feeding and aspiration status in medically complex children undergoing feeding therapy. Int J Pediatr Otorhinolaryngol, 2019. 127: p. 109646.
- 14. Alrwaily, M., et al., **Stabilization exercises combined with neuromuscular electrical stimulation for patients with chronic low back pain**: a randomized controlled trial. Braz J Phys Ther, 2019. 23(6): p. 506-515.
- 15. Qi, Y.C., et al., Therapeutic Effect Evaluation of Neuromuscular Electrical Stimulation With or Without Strengthening Exercise on Spastic Cerebral Palsy. Clin Pediatr (Phila), 2018. 57(5): p. 580-583.
- 16. Elbasan, B., et al., Effects of neuromuscular electrical stimulation and Kinesio Taping applications in children with cerebral palsy on postural control and sitting balance. J Back Musculoskelet Rehabil, 2018. 31(1): p. 49-55.

- 17. Serel Arslan, S., et al., Effect of Swallowing Rehabilitation Protocol on Swallowing Function in Patients with Esophageal Atresia and/or Tracheoesophageal Fistula. Eur J Pediatr Surg, 2017. 27(6): p. 526-532.
- 18. Pool, D., et al., Neuromuscular electrical stimulation-assisted gait increases muscle strength and volume in children with unilateral spastic cerebral palsy. Dev Med Child Neurol, 2016. 58(5): p. 492-501.
- 19. Neyroud, D., et al., Wide-pulse-high-frequency neuromuscular electrical stimulation in cerebral palsy. Clin Neurophysiol, 2016. 127(2): p. 1530-1539.
- 20. Karabay, I., et al., **Training postural control and sitting in children with cerebral palsy: Kinesio taping vs. neuromuscular electrical stimulation**. Complement Ther Clin Pract, 2016. 24: p. 67-72.
- 21. Elnaggar, R.K., Shoulder Function and Bone Mineralization in Children with Obstetric Brachial Plexus Injury After Neuromuscular Electrical Stimulation During Weight-Bearing Exercises. Am J Phys Med Rehabil, 2016. 95(4): p. 239-47.
- 22. McCain, K.J., M. Farrar, and P.S. Smith, **Gait recovery in a girl with ischemic spinal cord stroke**. Pediatr Phys Ther, 2015. 27(2): p. 190-9.
- 23. Karabay, I., et al., Short-Term effects of neuromuscular electrical stimulation on muscle architecture of the tibialis anterior and gastrocnemius in children with cerebral palsy: preliminary results of a prospective controlled study. Am J Phys Med Rehabil, 2015. 94(9): p. 728-33.
- 24. Coskun-Benlidayi, I., et al., Early rehabilitation of a child with intensive care unit acquired weakness secondary to membranoproliferative glomerulonephritis: A case report. Turk J Pediatr, 2015. 57(4): p. 422-425.
- 25. Yildizgoren, M.T., et al., Effects of neuromuscular electrical stimulation on the wrist and finger flexor spasticity and hand functions in cerebral palsy. Pediatr Neurol, 2014. 51(3): p. 360-4.