

International Hypotonia Society is a Not-for-Profit Corporation dedicated to the education and improvement of the quality of life of individuals impacted by the medical disorder known as Hypotonia.



International Hypotonia Society

# INTERNATIONAL HYPOTONIA SOCIETY

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International Hypotonia Society is a Not-for-Profit Corporation dedicated to the education and improvement of the quality of life of individuals impacted by the medical disorder known as Hypotonia. The Corporation will raise funds from the public which will be used to:

- (i) provide financial assistance and support to underprivileged families affected by hypotonia;
- (ii) provide resources and information to these families to assist in improving the life of individuals affected by hypotonia;
- (iii) fund other related not-for-profit organizations;
- (iv) fund Hypotonia research to better understand and deal with the condition; and
- (v) further the goals of the Corporation

This is dedicated to parents with children diagnosed with Hypotonia.

Ibrahim Ashemimry and Myriam Ghandour started the International Hypotonia Society after learning that their daughter, Hala Ashemimry was diagnosed with Hypotonia following her birth on November 2011. When she was born, she was unable to cry and doctors realized that she has some form of muscular weakness. Doctors immediately admitted her to Neonatal Intensive Care Unit (NICU) to better understand and care for her condition. She was then diagnosed with hypotonia and was in NICU for twelve days. This began their journey and discovery of this condition and how to treat their daughter Hala



When we first learned about Hypotonia, we had no idea what it meant or how it will impact our daughter's life. It was very devastating and scary to see our child in an incubator with feeding tubes and monitors attached to her. To better understand her condition, doctors put our daughter through many agonizing tests including MRIs, CatScans, EEG, ECG, blood tests, spinal tap, physical tests, & muscle biopsy. All tests came out normal, and the final diagnosis was that she had hypotonia.

Following her diagnosis, we were overwhelmed with fear, concern and uncertainty about her future and quality of life. To deal with it, we sought out several specialists world-wide in an attempt to assess and determine how to deal with our daughter's Hypotonia. Below is a list of the specialist we consulted with:

- Geneticist
- Pediatric Neurologist
- Pediatric Neurosurgeon
- Pediatric Cardiologist
- Radiologist
- Pediatrician
- Pediatric Orthopedist

Initially, our main questions were:

- Will she be able to eat?
- Will she ever sit?
- Will she ever walk?

- Will she ever talk?
- Will she be able to function cognitively?
- Will she ever develop physically?
- Will she ever be able to function independently and be self-sufficient?

Following her stay at NICU, the hospital recommended we see a neurologist. The neurologist, told us that Hala has a classic case of Spinal Muscular Atrophy (SMA), which is a very aggressive and deteriorating disease, and recommended we see a geneticist. The geneticist ran the SMA test and explained that most kids with severe cases of hypotonia like Hala's will not make it to their 2nd birthday.

We were horrified by this news and were anxiously awaiting the results of the SMA test, which took six agonizing weeks. Luckily, Hala's SMA test came out negative. In the midst of all of this, Hala's Pediatrician recommend immediate physical therapy multiple times on a daily basis. Her progress initially was slow, but there seemed to be a light at the end of the tunnel.

Once all the tests came out negative and the sole diagnosis was hypotonia, we travelled back to Saudi Arabia and continued Hala's daily physical therapy regimen. In Saudi Arabia they used a therapy called Medic therapy, which helped her significantly. Hala was able to sit without support by 9 months and walk by 17 months without going through the crawling phase. Even though she was able to sit and walk, it was clear to the observer that she had difficulty and weakness in performing those tasks, however; they were significant milestones for us and Hala. We later moved back to the US and continued with a wide range of therapies and she began to achieve several more milestones. This gave us hope for her future progress.

Ibrahim & Myriam

When treating hypotonia, early therapeutic intervention is the key to success. Hypotonia indicates decreased muscle tension or stiffness.

This may or may not be associated with muscle weakness. Hypotonia impacts the signal muscles receive to contract effectively. This can impact a child's ability to acquire new motor skills or complete motor activities with adequate endurance.

Occupational therapy can assist in areas which promote the development of fine motor skills, sensory processing/modulation, cognitive skills and activities of daily living.

Developmental skills build upon each other, therefore early intervention can ensure that a child is reaching their developmental milestones within age expectancy. Hypotonia may impact an infant's ability to participate in important developmental activities that require muscles to activate and sustain weight-bearing positions.

Occupational therapy can help early on to address the skills that involve the use of the muscles for weight-bearing, such as those associated with "tummy-time". These positions are an important foundation for reaching future developmental milestones such as rolling, transitional movements for sitting, and crawling.

Hypotonia may also affect a child's ability to gain adequate postural stability or control. Without a stable base of support, it is difficult to gain sufficient distal control needed for fine motor skill development. Occupational therapy helps to address a child's postural stability and control for functional participation in activities of daily living such

as feeding, dressing and self-care tasks. Occupational therapy also helps in the development of hand function and fine motor skills, such as handwriting.

During occupational therapy, a variety of therapeutic interventions are used to help a child learn new skills. Neurodevelopmental treatment is a common approach to encourage typical movement patterns through therapeutic handling techniques. Sensory Integration is often used as well to improve a child's motor planning and body awareness. In conjunction with occupational therapy services, a comprehensive home program is helpful to provide parents and caregivers with activities to do at home. Home activities are an integral part of a comprehensive treatment plan.

Suggestions for Home Activities:

- Give your baby opportunities for movement with supervised "tummy-time" while your baby is awake. Place your baby on a safe surface, such as a child foam mat. Lay in front of your child and encourage him/her to lift their head to see you. Your face and voice are very motivating to your baby! You can also use child-safe mirrors, music or brightly colored toys to encourage your baby to remain propped on their forearms with their head lifted.
- Reaching activities are also a nice way to help your child develop the muscles in their arms. With your baby lying on their back on a flat, safe surface, gently swipe a soft toy/rattle inside your baby's hand to encourage them to open their hand. As your baby's arm moves, encourage them to reach towards the toy and grasp it. You can gradually hold the toy higher to help your baby

promote proximal strength, endurance and motor coordination. Dance and karate can also be good choices. Activities should focus on getting their muscles active through body movements, which will help promote functional use and endurance in everyday tasks.

Every child is individually unique, and your occupational therapist can provide a detailed home program specific to your child's needs.

Contributed by Raine Coleman, Occupational Therapist



Hypotonia, a condition of decreased muscle tone which significantly impact feeding, swallowing, oral-motor mechanism and speech development. Therefore, once hypotonia has been diagnosed the child should be seen by a speech language pathologist for a complete speech and language evaluation. The evaluation must be performed by a licensed and certified Speech Language Pathologist. Speech language pathologist may assess the following:

- Oral-motor mechanism
- Feeding
- play skills
- receptive language skills
- expressive language skills
- social pragmatic skills
- speech development

Early collaborative intervention, as well as parental involvement is imperative for success and optimal outcomes. When working with your child always remember to have fun; play is best with constant positive reinforcement.

Fun ideas to improve oral structures:

- Have your child blow musical instruments, bubbles, or even cotton balls through a straw.
- These fun activities will help with lip closure and strengthening of lips, jaw, and cheeks as well as the diaphragm (muscle of respiration).

- Have your child hold a tongue depressor between her lips and hum (Happy Birthday song), (ABC's), or any other short songs. These activities will help strengthen lips, among other structures.

- Have your child be "silly" and make funny faces to improve overall strength, coordination, and range of motion of the lips, jaw, and tongue.

- Have your child blow on a window/mirror to make fog. This helps with coordination of breathing and lip movement.

- Have your child imitate animal sounds such as: monkey, dog, elephant, lion, etc. to improve overall range of movement for the oral motor musculature.

I hope this information is helpful and always be an active participant in your child's therapies.

Contributed by Diana Ramirez, Speech Language Pathologist



Would you Consider a donation for \$10, \$25, \$50, \$100 or \$500 please make dontations to our paypal account of [info@hypotonia.org](mailto:info@hypotonia.org) for your desired amount.

Thank you

International Hypotonia Society is a not for profit corporation dedicated in furthering knowledge of the medical disorder known as Hypotonia. We thank you for visiting [hypotonia.org](http://hypotonia.org). We encourage for you to share your experiences with us. Please write to us. We also use your donations to maintain this website. Thank you for your donations.

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