GUIDELINES
Orthopaedic treatment
(Infants and Children)
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Spina Bifida and Hydrocephalus Panel Gulf Area - (SBHPGA)
“Give them fish and feed them for a day; teach them how to fish and feed them forever”

Background and aims: The SBHPGA was formed in June 2009 based on an idea from Dr. M. Patricolo and Dr. S.A. Wasti, respectively the Chair of the SBHPGA and WFNR Ambassador to the Vice President of WFNR – Gulf Area Section, the first, and Vice President of WFNR Gulf Area Section, the second. The 1st Reunion of the SBHPGA and its 1st Meeting took place in Abu Dhabi, UAE, on the 23rd of March 2010. During the 1st Meeting of the SBHPGA it has been decided that the Panel should produce standardized guidelines for management of patients affected by the relevant conditions, to standardize and “equalize” level of care, in all the Arabian Gulf Countries. During the 1st Reunion of the SBHPGA, the Panel has extensively discussed guidelines applied in each of the 8 Countries involved. The present document will summarize and integrate orthopaedic guidelines for the neonatal period. After collegial revision, the guidelines will be sent for publication on a chosen peer review journal, as standardization document, along with the guidelines for perinatal, transitional and adult ages.

Prenatal counseling

Methods of early diagnosis such as ultrasound now give the parents the opportunity to know the condition of their baby before birth. The parents who have been given a diagnosis of spina bifida (SB) for their unborn child should be offered prenatal
counseling (not linked to termination of pregnancy) by skilled professionals in a multidisciplinary team involved in the treatment of SB. It should be comprehensive, discussing all aspects of life with a child with SB. Information should be up-to-date and understandable by parents. Parents must feel free and informed to make a choice whether to terminate or continue the pregnancy.

Post natal care

Whether the patient is first evaluated on the ward or in the clinic, the Physician should dedicate sufficient time to history taking and to examination of physical conditions. A minimum of 30-45 minutes is strongly encouraged. Ideally an Orthopaedist and a Physiotherapist should be involved in a Multidisciplinary Clinic or Consultation.

Detailed history taking should be obtained and reported on a “Nosographic Chart” (see attached file), and in the patient file.

General physical examination and neurologic examination should be thorough. The orthopaedic surgeon will specifically examine:

- Spine: -deformities in the sagital and coronal planes
- Hips: -dislocations and/or contractures
- Knees: -contractures in flexion or extension
- Feet: -clubfeet, vertical talus, calcaneus, other deformities
- Skin: -pressure sores
- Neuro: -level of paralysis and motor function of the lower extremities

The goal of orthopaedic care in the neonatal period is to avoid contractures and to correct deformities in order to allow the patients to eventually function at the maximum level permitted by their neurological lesion. The potential for walking independently will likely be a concern for the parents and explanations should be given in light of the physical findings. We have to keep in mind that mobility and independent living implies more than walking and this should be reinforced.

ORTHOPAEDIC MANAGEMENT

Spine

The spine, apart from the midline lesion, rarely presents with significant deformity at birth. Congenital scoliosis may be present in SB and imaging should be carefully evaluated. Syringomyelia can also be associated and should be ruled out. These curves are more likely to progress in infancy compared to the more common paralytic scoliosis seen in SB and therefore will require close follow-up.

Hip/Knee
Paralysis (any level) that can lead to muscle imbalance and dislocation of the hips is a frequent finding in patient with SB. The goal of treatment in the neonatal period is to prevent contractures of the hip more than to relocate the hips at any cost: it has been shown that the potential for walking depends on the level of the paralysis and not on the position of the hips. Hip relocation procedures will eventually be considered mostly for unilateral dislocations in a low level neurologic lesion, keeping in mind the risk of redislocation despite muscle balancing procedures. Regular stretching exercises at home and under the supervision of the physical therapist will help maintain a symmetrical hip range of motion.

Knee flexion or extension contractures can be gently manipulated weekly and serial casting can be effective to correct deformities. Physical therapy will be necessary to maintain the range of motion. Surgery will have to be considered if the residual deformity will not allow proper brace fitting (more than 20 degrees of flexion).

**Foot/Ankle**

The goal of orthopaedic treatment in babies is to obtain a flexible and easily braceable foot. Shortly after birth, a trial of serial casting is initiated. However, particularly for the clubfoot or the vertical talus, the deformity is stiff and will require surgical treatment more frequently than the idiopathic clubfoot. Attention to detail is crucial in order to avoid pressure sores to the feet when casts are applied. Once correction is obtained, bracing and close follow-up will be important to prevent or detect recurrence.

**SPINA BIFIDA CLINIC**

A SB Multidisciplinary Clinic should be run an average of 2 times a month.

It should see an integrated team formed by a Pediatric Surgeon/Urologist, a Pediatric Neurosurgeon, a Pediatric Orthopedist, a Pediatric Nephrologist a Physiotherapist and/or O.T. and a Neuro-rehabilitation Physician.

The team should be supported by two specialized senior nurses, one of which should also be a continence advisor.

Appointments with each member of the team should be of at least 30 minutes and a first appointment with the Pediatric Surgeon/Urologist, should last at least 45 minutes, to guarantee a full “History & Physical” allowing time for explanation, basic investigation and planning for followup. Imaging and other investigation should be planned on the same date of the clinic appointment, prior to the consultation. Ideally a SB clinic should be a Day Hospital (Day Care) Admission.

Patients and their relatives should be involved, explained imaging and lab results, taught procedures and given a hotline number to talk to a nurse or to a physician, if required,
every day, during working hours. Six monthly audits of the clinic activity should rigorously be performed by the SB Clinic Team.

The transitional ages should be treated accordingly to the SGHPGA guidelines for adolescents and adults.

*These guidelines for the orthopaedic management of Spina Bifida in the neonatal period are the result of the revision of the presentation obtained by the 1st Reunion of the SBHPGA (23rd of March, 2010, Abu Dhabi, UAE) and the input of their authors.*

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