# *Spina Bifida Clinics*

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When we speak about *Spina Bifida, Hydrocephallus* and other Vertebral Anomalies we must highlight some points:

- A person with Spina bifida is a part of our community and as such is part of pediatric patient population.
- While there are some medical condition are more common, there is nothing unique or outside the scope of general pediatrician involvement.
- The key to good quality care is to be familiar with the condition, but more important, to know the person and his family.
- Medical management, home environment, education and vocational training can significantly affect the level of function of children with *Spina bifida*.
- Several areas require ongoing assessment throughout childhood and should be reviewed periodically at developmentally appropriate ages.
- Pediatricians are the primary resource for counseling, starting even prenatally and continue throughout childhood.
- Presence of *Spina bifida* Clinics will organize the management program in highly qualified type of care, decreasing effort, maximizing benefit of family and child.

## *MISSION of SPINA BIFIDA CLINICS:*

- Our mission is to provide highest quality of care, while ensuring efficiency and proper utilization of available resources (*no special budget*).
- Quality of care is to be measured by better clinical outcome and family satisfaction.

## *GOALS:*

- To provide excellent and well organized management program.
- Treatment of acute and chronic problem.
- Well Baby Clinic follow-up and immunization.
- Early detection of disability and disease.
- Family support and advisory center.
- Motivation of family for better home care.
- Resource center of information about *Spina bifida*.
- Site for consultation with other specialty.
- Study and research.

# *SPINA BIFIDA* CLINIC SET-UP

LOCATION

Pediatric Clinics

FREQUENCY

- clinics per month (one for immunization).
- Clinics number will increase when needed

PERSONNEL

- Pediatrician: who has a good experience and knowledge in *Spina bifida*,
- Interested to run this type of clinic, will be the team leader (Organizer).
- Pediatric neurology.
- Neurosurgury.
- Pediatric urology
- Pediatric gastroentrology
- Pediatric orthopedic.
- Health Educator who trained in *Spina bifida*.
- Social Service: who trained in *Spina bifida*.
- Nursing staff.

SUPPORTIVE SPECIALITY (on referral basis)

- Physiotherapy
- Dietition

SPACE

- 2-3 rooms for MD
- 1 room for health educator, social services.
- 1 screening room
- 1 immunization room
- Waiting area for Male & Female

MATERIAL

- Videotapes: will provide in waiting area
- Pamphlets, books about *Spina bifida* will provide to patient during
- Education session
- Direct education by picture & posters

## *SPINA BIFIDA* CLINIC ACTIVITY

*Regular & Organized Follow-up (follow-up protocol)*

- First sitting with parent after delivery by neonatologist, team must be available , guideline for first meeting, breaking the news ,must be organised ( WHO? WHAT ? TO WHOM? ) What is the role of each person in the team.
- Regular follow-up depending on patient medical condition concentrating in Well Baby Clinic schedule appointments where immunization, growth parameter &education is provide.
- Regular investigation depending on the condition.
- Regular referral to other speciality e.g. Physiotherapy, Dietition if needed.

*Treatment of Acute & Chronic Disease*

- Early detection of disease & disability.
- Prevention.

*Family Education (center of education)*

- This will be provided in each visit, concentrating in one subject each visit.
- Physician, health educator, social service are the advisory & education team.
- Education subjectabout *Spina bifida* , This will be provided in each visit, concentrating in one subject each visit which include : cause, congenital abnormality, physical development & its delay, mental development & mental retardation
- How to improve physical & mental development.
- Schooling
- When to ask for medical advice
- Family to family site of changeable experience.
- Site for family confidence.

*Family Support (center of advisory)*

- financial support
- social support
- pre-school education
- school education

CONCLUSION

*Spina bifida* clinics is part of ambulatory pediatric clinics, which will provide excellent and organized follow-up for these patient, patient & family satisfaction, interaction and cooperation will be the approach for huge improvement in life quality of patient & their family.

# *Spina Bifida Clinics Guidelines*

## INFANT: FIRST YEAR OF LIFE

The first twelve months of life is referred to as the infant state. During this time, the development of trust is basic to growth and development. This occurs when the infant's need for food, warmth, safety and human interaction are met on a consistent basis. Strong parent-child bonding occurs.

### *I. Pediatricians*

*Each child who has spina bifida needs general pediatric care as well as specialty care.*

A. Consult with appropriate *spina bifida* team members when problems related to *spina bifida* arise.
B.Each child with *spina bifida* needs general pediatric care as well as specialty care.
C.Pediatric expertise provides an essential base in normal growth and development.
D. Provide well baby checks, including growth and development assessment.
E. Institute immunization.
F. Treat episodic illnesses not related to *spina bifida*.
G. Refer to an ophthalmologist if problems are evident.
H. Routine referral to an ophthalmologist at 6 moths.
I. Assess hearing ability.
J. Assess neurological development.
K. Provider for continuity of care.
L. Serve as resource of information for parent & team members.

### *II. Neurosurgery*

*Maintenance of normal intracranial pressure will preserve brain function.*

A. Follow-up to assess shunt and central nervous system function every three months or more frequently as specified by the neurosurgeon.
B. Obtain an ultrasound or CT of head or MRI of head and spine as needed.
C. Teach sign & symptoms of shunt malfunction to parents
D. Monitor head circumference
E. Assess for Chair malformation symptoms

### III. Orthopedics

*Bones and muscles need to be in functional alignment in preparation for mobility devices.*

a) Assess a minimum of every three months
b) Evaluate and treat deformities in preparation for bracing
c) Apply corrective casting
d) Prescribe appropriate orthotic devices, splints.
e) Initiate a standing frame when appropriate.
f) Evaluate neurological level to predict future deformities/problems and direct preventive care.
g) Perform appropriate foot and hip surgery.

## IV. Urology

*Controlling urinary tract infections and bladder pressure will prevent kidney damage.*

a) Obtain a urinalysis, culture and sensitivity, as needed each clinic visit with appropriate follow up .
b) Follow-up renal ultrasound and/or other diagnostic tests as needed at 3, 6, 12 months.
c) Teach signs and symptoms of urinary tract infection.

## *V. Nursing & Health Educator*

*Understanding treatment regimes is basic to follow through.*

A. Assess age-appropriate growth and development and coordinate referral as necessary.
B. Reinforce teaching to parents regarding spina bifida and treatment regime.
C. Stress the importance of good hygiene practices .
D. Provide patient advocacy.
E. Assess progress and problems at each clinic visit.

## VI. Physical/Occupation Therapy

*Physical therapy on a regular basis is important for sensorimotor development and the prevention of deformities.*

A. Perform follow-up evaluation at 6, 12 months, including neuromotor development and strength assessments.
B. Provision of training with orthotic equipment.
C. Obtain occupational therapy evaluation at 3 to 6 months.
D. Establish a physical therapy and home program for normal sensorimotor stimulation.
E. Evaluate and revise programs to develop motor skills and perceptual motor development.

## VII. Social Services

*Knowledge of a variety of community resources will help parents know that help is available.*

A. Reassess family condition.
B. Continue referral to community services (Financial, Educational, and Social
C. Provide additional support as needed.
D. Advise parents for child education.

## VIII. Nutritional Services

*Proper nutrition will promote progress in growth and development.*

A Assess weight and height gain and counsel accordingly.
B. Provide information on high fiber diets for bowel management.
C. Identify and address feeding problems.

## Summary of Priority Outcomes for the Infant

**1.Normal intracranial pressure is maintained.**
**2.Bones and muscles are in functional alignment.**
**3.Bladder pressure is within the range of normal.**
**4.Urinary tract infections are controlled.**
**5.Infant is within the normal range for length and weight.**
**6.A pediatrician or family practice physician is providing primary medical care.**
**7.Parents are receiving adequate information and supportive services.**

# TODDLER: 1-3 YEARS

The first to the third year of life is referred to as the toddler stage. During this time this child experiments with holding on and letting go (control issues) and begins to attach enormous value to will power. Extensive exploration of the environment occurs. This is the beginning of independence. For growth and development to progress, the child needs to have appropriate opportunities to express autonomy. Parents play a vital role in encouraging safe, appropriate independence.

## I. Pediatricians

*Each child who has spina bifida needs general pediatric care as well as specialty care.*

- Pediatric expertise provides an essential base in normal growth and development, deviations from the norm and appropriate treatment protocols for the toddler.
- Complete a general physical examination frequently (3-6 month) as indicated, including growth & development assessment & immunization.
- Treatment of episodic illnesses not related to *spina bifida*.
- Referral for eye evaluation and other referrals as needed (dentist, other specialist.(
- Consult with appropriate *spina bifida* team members when problems related to *spina bifica* arise.
- Provide for continuity of care.

## II. Nuerosurgery

*Maintenance of normal intracranial pressure will preserve brain function.*

a) Follow-up every 4 -6 months
b) Assess central nervous system (symptoms of tethered cord, hydromyelia, Chiari malformation.
c) Assess shunt status (CT scan / MRI if indicated)

## III. Orthopedics

*Bones and muscles need to be in functional alignment in preparation for mobility devices.*

A. Assess orthopedic status every 4 -6 months
B. Prescribe appropriate orthotic devices for ambulating/adaptive equipment.
C. Perform corrective surgeries as needed.
D. Follow-up orthopedic X-rays
E. Assess the configuration of the spine
F. Assess physician and occupational therapy needs and prescribe treatment.

## IV. Urology

*Controlling bladder infections and bladder pressure will prevent kidney damage.*

A. Assess renal status every 6 months
B. Obtain renal/lab. Studies as indicated
C. Follow-up urine cultures every 6 months as indicated
D. Monitor the medication regimen
E. Discuss toilet training (bowel and bladder) with the parents of these are no contraindications.

## V. Nursing & Health Educator

*Parental knowledge of normal growth and development is as important as all the specialty issues related to spina bifida.*

A. Provide anticipatory guidance (i.e., safety issues, limit setting, discipline), supportive counseling, Crisis intervention.
B. Teach family appropriate bowel and bladder training methods to neurogenic bladder and bowel.
C. Stress the importance of good hygiene practices
D. Encourage patients to set limits/discipline the child
E. Teach skin management relative to orthosis and cast care.
F. Provide information about community resources schooling, etc
G. Encourage self-care abilities
H. Assess progress and problems at each clinic visit

## VI. Physical/Occupational Therapy

*Physical/occupational therapy on a weekly basis is important for sensorimotor development and the prevention of deformities.*

A. Perform a physical therapy evaluation every 6 months, including assessment of muscle strength and neuromotor development.
B. Stabilize in a standing position; beginning gait training.
C. Provide mobility training with assertive devices as needed
D. Teach physical therapy exercises and home program for stimulation of normal sensorimotor development.
E. Evaluate bracing problems and needs
F. Communicate between the physical and occupational therapists, orthopedist and orthotist.
G. Evaluate and revise programs to promote motor skills and perceptual motor development.

## VII.Social Services

*A variety of community resources will help parents know that help is available and they are not alone.*

A. Assess family status annually and intervene as indicated
B. Refer to community services, financial resources
C. Provide supportive interventions
D. Continue to screen for acquisition of developmental milestones
E. Perform (refer) psychometric testing for preparation into early intervention school programs.

## *VIII. Nutritional Services*

*Proper nutrition will promote progress in growth and development.*

A. Provide instruction and monitor dietary patterns annually and as indicated.
B. Continue to assess height and weight
C. Stress the importance of a high fiber, high fluid diet
D. Counsel regarding weight control
E. Plan nutritional programs that incorporate fast food menus

## Summary of Priority Outcomes for the Toddler

1. Normal intracranial pressure is maintained
2. Optimum mobility is achieved
3. Bladder pressure is within the rage of normal
4. Urinary tract infections are controlled
5. A bowel continence program is started
6. Child is within normal range for height and weight
7. Child is enrolled in an early intervention school program (if present
8. Parents are receiving adequate information and supportive services

## PRESCHOOL: 3-5 YEARS

The third year through the fifth year of life is considered the preschool stage. During this stage the child wants to know about and do everything. A beginning understanding of boy/girl roles, body image, and body boundary develops. Much is explored through imagination. Parents can do a lot to encourage their child's need to know and understand, so that growth and development will progress. A learning self-care skill becomes important.

### I. Pediatricians

*Each child who has spina bifida needs general pediatric care as well as specialty care.*

A. Pediatric expertise provides an essential base in normal growth and deviation.
B. Complete a general physical exam each year, including growth and development assessment.
C. Monitor and provide immunizations
D. Treat episodic illnesses not related to *spina bifida*.
E. Provide parent guidance
F. Refer for an eye evaluation if not already performed
G. Refer for a dental evaluation (craniofacial)
H. Consult with appropriate *spina bifida* team member when problems arise related to *spina bifida*.
I. Provide for continuity of care

### II. Neurosurgery

- Maintenance of normal intracranial pressure will preserve brain function
- Early detection of problem areas allows for close monitoring and early treatment.
- Follow-up every six months to assess shunt function and presence of tethered cord, hydromyelia and Chiari malformation symptoms.

### III .Orthopedics

*Optimum mobility is achieved through regular orthopedic evaluation and follows through.*

A. Assess the orthopedic status every 4 -6 months
B. Assess orthotic devices for proper fit and appropriateness
C. Perform corrective surgeries as needed
D. Follow-up orthopedic X-rays
E. Consider a prescription for wheelchair, if appropriate
F. Assess the configuration of the spine

### IV .Urology

*Controlling bladder infections and bladder pressure will prevent kidney damage . School readiness often includes getting the child socially continent (dry with catheterization.(*

A. Institute clean intermittent catherization (CIC) and pharmacotherapeutics, as indicated.

B. A follow-up bowel program
C. Obtain renal /lab studies as indicated every 6-12 months
D. Obtain urine culture when indicated

## V. Nursing & Health Educator

*Parental knowledge of normal growth and development is as important as all the specialty issues related to spina bifida.*

A. Institute a bowel continence program
B. Discuss school readiness regarding care (as catheterizatrion
C. Assess growth and development
D. Institute and reinforce any new teachings.
E. Foster independence
F. Stress the importance of good hygiene practices
G. Identify and refer to resources that promote independence
H. Assess progress and problems at each clinic visit
I. Serve as a resource to school systems regarding health issues of children with *spina bifida*, bowel management, clean intermittent catheterization.

## VI. Physical/Occupational Therapy

*Physical/occupational therapy on a weekly basis is important for sensorimotor development and the prevention of deformities.*

A. Assess fine motor/gross motor skills and perform annual muscle strength testing. Give particular attention to hand-eye coordination.
B. Check orthotic equipment
C. Communicate with the school therapist
D. Evaluate readiness for the introduction of the developmental tasks of daily living (i.e., self catheterization transfers.(
E. Assess mobility need and mobility training
F. Update the evaluation of eating skills
G. Refer for speech/language evaluation as needed
H. Evaluate preschool preparation.
I. Facilitate communication between physical and occupational therapists, orthopedist and orthotist.

## VII. Social Services/Psychology

*Use of appropriate school and community resources will help maximize the child's potentials.*

A. Obtain medical psychologist testing (psychometrics, psychoeducational) at 3 years and 5 years by a school psychologist.
B. Assess the establishment with a school and evaluate educational potentials.
C. Assess family coping
D. Assess parenting skills (discipline, behavior management techniques).
E. Identify community resources and refer appropriately
F. Provide counseling and behavioral management
G. Establish communication between health care center and community resources to enhance integration into programs.

## VIII. Nutritional Services

*Proper nutrition will promote progress in growth and development*

A. Assess height/weight proportion
B. Stress diet management appropriates for age and physical condition
C. Teach and monitor healthy family eating patterns
D. Stress the importance of a high fiber, high fluid diet.
E. Plan nutritional programs that incorporate fast food menus

## Summary of Priority Outcomes for the Preschooler

1. Normal intracranial pressure is maintained.
2. Optimum mobility is maintained.
3. Bladder pressure within the range of normal.
4. Urinary tract infections are controlled.
5. Bowel and urine control to the level of social continence.
6. Child's weight is within a normal range for height and weight.
7. Child is enrolled in an appropriate preschool program.
8. Parents and child are receiving adequate information and supportive services.

## SCHOOL AGE : 6-11 YEARS

The sixth year through the eleventh year are referred to as the school-age stage. It is a time when the child needs to feel mastery and completion of tasks and projects and be recognized for them. This will contribute to self-esteem and self-confidence. Peers become increasingly important. Parents can do a lot to facilitate peer socialization and a feeling of recognition for what is accomplished.

### 1.Pediatricians

*Each child who has spina bifida needs general pediatric care as well as specialty care.*

A. Pediatric expertise provides an essential base in normal growth and development, deviations from the norm and appropriate treatment protocols for the school age child.
B.Perform a physical exam and developmental assessment annually.
C. Discuss development of early puberty with girls and short stature
D. Reinforce good dietary practices
E.Assure current immunization status
F.Treat episodic illnesses not related to *spina bifida*.
G. Consult with appropriate *spina bifida* team members when problems arise related to *spina bifida*.

### II. Neurosurgery

*Maintenance of normal intracranial pressure will preserve brain function*
*Early detection of problem areas allows for close monitoring and early treatment.*

A. Follow-up every 6 months to assess shunt function and presence of tethered cord, hydromyelia and Chiari malformation symptoms.
B. Determine shunt tube length adequacy in relation to growth
C.Teach child about *spina bifida* /signs and symptoms of increased intracranial pressure.

### III. Orthopedics

*Optimum mobility is achieved through regular orthopedic evaluation and follow-through.*

A. Follow-up every 4 -6 months
B. Address mobility issues
C. Assess adaptive equipment and mobility devices
D. Perform orthopedic surgeries
E. Prescribe adaptive physical education, physical therapy and occupational therapy.
F. Teach the child about fractures and related precautions
G. Monitor the development of scoliosis /kyphosis

### IV. Urology

*Controlling bladder infections and bladder pressure will prevent kidney damage.*
*Social continence is basic to self acceptance and acceptance by others*

A. Follow-up annually with ultrasound
B. Teach the child signs and symptoms of urinary tract infections and medications and treatments for these infections.
C. Follow-up with bowel and bladder continence.
D. Repeat other urology testing as needed (including urine cultures
E. Institute self clean intermittent catheterization as the child shows readiness .

## V. Nursing & Health Educator

*Learning self-care is basic to a positive self-image and progress towards independence.*

A. Reinforce proper teaching, as needed (skin care, prevention of urinary tract infections, fractures

B. Teach self care activities (catheter, bowel, skin safety techniques, application of splints or braces

C. Monitor growth and development (include the child in teaching and recognize their need for concrete examples and approaches.

D. Stress the importance of good hygiene practice

E. Continue to function as an advocate/liaison community resources

F. Assess the child's perception and basic knowledge of his/her condition.

G. Assess progress and problems at each clinic visit

H. Serve as a resource to school systems regarding health issues of children with spina bifida, bowel management and clean intermittent catheterization.

## VI. Physical/Occupational Therapy

*Physical/occupational therapy maintains muscle strength and prevents deformities.*

A. Address activity of daily living issues

B. Teach transfer techniques

C. Teach wheelchair management/propulsion

D. Continue with gait training

E. Perform a complete physical therapy evaluation annually, including muscle strength.

F. Reinforce skin care issues and pressure awareness

G. Refer for speech/language evaluation when indicated

H. Facilitate communication between the physical and occupational therapist, orthopedist and orthotist.

I. Design an exercise program for each child and counsel them regarding implementation.

## VII. Social Services & Psychologist

*Use of appropriate school and community resources will help maximize the child's potential.*

1. Obtain medical psychology testing.
2. Assess family relationships with the school
3. Provide one-to-one counseling with child
4. Provide behavioral management counseling services
5. Evaluate school achievement and status regarding appropriate school placement.
6. Encourage parents to teach child consequences of behavior/choices.
7. Mobilize community resources on behalf of the child and family.
8. Continue a liaison with community resources, focusing on current treatment plans .

## VIII. Nutritional Services

*Proper nutrition will promote progress in growth and development.*

A. Review and assess diet
B. Incorporate the child in teaching, questions, choices (include family Counsel regarding weight control
D. Stress the importance of a high fiber, high fluid diet
E. Plan nutritional programs that incorporate fast food menus.

**Summary of Priority Outcomes for the School-Age:**

1. Normal intracranial pressure is maintained
2. Optimum mobility is maintained
3. Bladder pressure within the range of normal
4. Urinary tract infections are controlled
5. Child is becoming independent in bowel/bladder management, brace application, skin checks, and other self-care activities.
6. Child's weight is within a normal range for height and weight.
7. Follows a regular exercise program
8. Child is enrolled in an appropriate grade school.
9. Parent/child are receiving adequate information and supportive services.