

# Delayed Referral for Intrathecal Baclofen Therapy in Pediatric Patients with Severe Spasticity: What do Parents Think?

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### Introduction

Intrathecal baclofen therapy (ITB) has been used in the treatment of patients with spasticity and dystonia. In our pediatric movement disorders clinic, we noted a significant delay in the referral of patients for consideration of ITB. Often, it is only after years of failed medical therapy that a baclofen pump is considered. This study attempts to investigate the prevalence, length and causes of the delay in order to improve the quality of life for our patients.

### Methods

A retrospective outcome analysis was performed. We conducted a survey of 22 pediatric patients who received pumps between the ages of 5 and 23, after ITB approval by the US Food and Drug Administration in 1996. Parents were consented and completed the survey on their child's behalf for those who were not able to communicate due to their condition. Causes of spasticity include anoxic brain injury (9 subjects), cerebral palsy (9), hereditary spasticity (2), spinal cord injury (1), and viral encephalitis (1). Information was collected regarding their onset of spasticity, attempted treatments, pump referral, satisfaction, and resulting change in the quality of life.

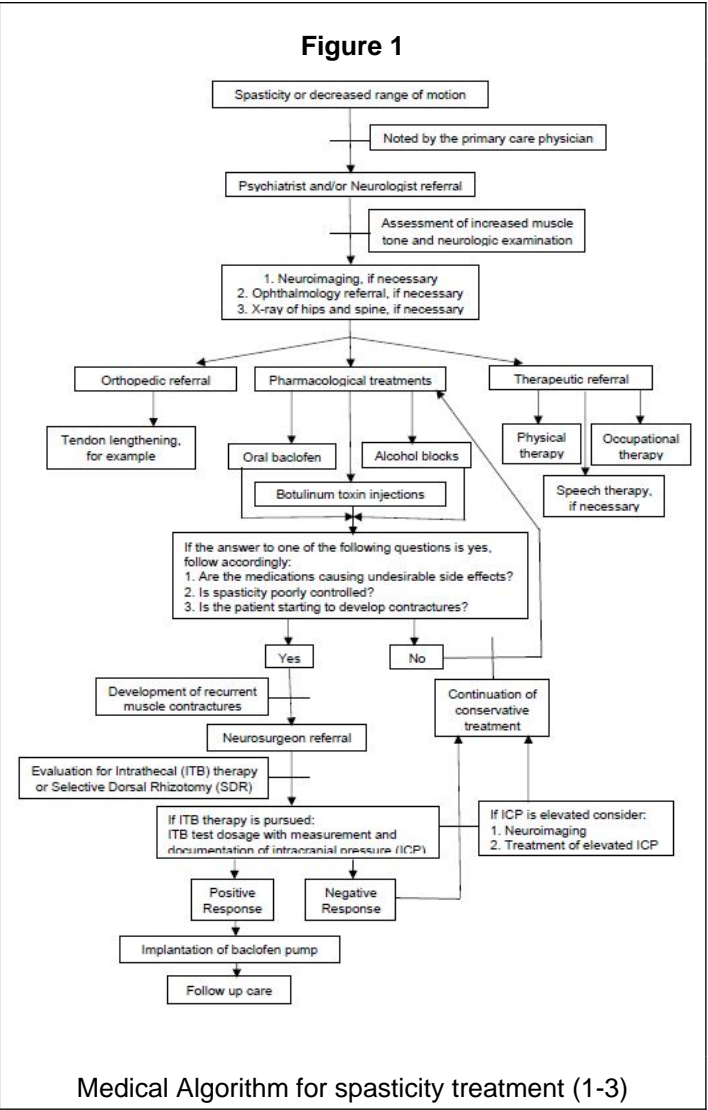
Table 1

Subject	Cause of spasticity	Age of onset of spasticity (years)	Age at ITB implantation (years)	Delay of ITB referral (years)
1	ABI	13	13	0
2	ABI	12	13	1
3	ABI	17	18	1
4	ABI	18	19	1
5	ABI	22	23	1
6	VE	13	15	2
7	ABI	16	18	2
8	ABI	18	20	2
9	ABI	17	19.5	2.5
10	ABI	18	21	3
11	CP	0	5	5
12	SCI	5	10	5
13	CP	9	14	5
14	ABI	0	7	7
15	CP	0	7	7
16	HS	2	10	8
17	CP	0	9	9
18	CP	2.5	12	9.5
19	CP	1	11	10
20	HS	2	12	10
21	CP	0	11	11
22	ABI	4	15	11

Length of delay of ITB referral after approval (1)

### Results

There was a delay in referral in most cases investigated. Average time to baclofen pump implantation after initial onset of spasticity was 5.14 years, with the longest delay being 11 years. All patients reported ineffective pharmacological treatment, but 91% of these subjects reported that ITB was long-lasting and effective (Table 1). 20 out of the 22 subjects also reported an improved quality and ease of life.



### Conclusion

Despite the limitations of this subjective retrospective analysis of outcomes and delay in referral, the opinions of the parents and caregivers are important. Earlier referral for ITB therapy may better treat severe spasticity in pediatric patients. An increased awareness of this treatment earlier on in the disorder may reduce the delay of ITB referral, potentially improving the patient's quality of life.



### Learning Objectives

1. Describe the importance of earlier referral for ITB therapy to better treat severe spasticity in pediatric patients
2. Discuss in small groups the effectiveness of pharmacological treatment versus ITB therapy
3. Identify the delay in the referral of patients for consideration of ITB

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