

## TUBEROUS SCLEROSIS JOURNAL

*An organizational diary for the care and treatment of tuberous sclerosis*

### **Foreword**

Because the treatment of tuberous sclerosis may involve a variety of health care professionals, it is very useful to have a working system to track ongoing medical care and treatment. This journal was specifically designed to provide you with an organized way of keeping accurate records of medications, procedures, appointments, therapies, surgeries, tests and manifestations.

It is never too late or too early to start using the journal. Regardless of how long ago a patient was diagnosed with tuberous sclerosis, or the extent to which a patient is affected, this journal will enable you to consolidate and organize vital clinical information.

The journal is extensive, yet flexible. There may be sections you won't need, and other sections that need to be modified for your particular situation. It is adaptable by design and thorough in its scope so that you can effectively tailor it to your needs.

In addition to helping you keep track of all the pertinent information, you may use the journal to provide physicians and specialists with an overview of procedures and results, summaries of tests, a list of other involved professionals, and the patient's current treatment plan. Also enclosed in the journal are the diagnostic criteria and follow-up recommendations from the 1998 National Institutes of Health-sponsored Tuberous Sclerosis Consensus Conference, as well as applicable *Fact Sheets*.

### **Disclaimer**

The *Tuberous Sclerosis Journal* was composed and compiled by a group of parents who have children with tuberous sclerosis, and individuals who believe in the importance of this project. Although medical professionals have reviewed the journal contents, the journal neither provides nor is a substitute for expert medical advice. The people involved in this project do not suggest or recommend any specific treatment, drug, action or therapy. It is important to be aware that not all people with tuberous sclerosis will have manifestations in every category listed in this journal. The headings of the journal and the list of testing recommendations are given solely as possible guidelines and general resources.

# introduction

## INTRODUCTION

### **Introduction**

*by Hope Northrup, M.D.*

The *Tuberous Sclerosis Journal* will not only empower you, but also your physicians. By taking it to each and every office visit, you will allow the doctors to spend more time with you discussing current problems, and less time reviewing previous visits or catching up on what has occurred during visits with other specialists.

The journal also provides the currently recommended guidelines from a panel of tuberous sclerosis experts about when your child needs specific follow-up testing. This information will help your doctor appropriately treat your child.

**Be sure to take it with you to all doctor visits!**



**INFORMATION**

**PATIENT INFORMATION**

Patient Name: \_\_\_\_\_

Address: \_\_\_\_\_

\_\_\_\_\_

Telephone: \_\_\_\_\_ E-mail: \_\_\_\_\_

Social Security No.: \_\_\_\_\_

Insurance No.: \_\_\_\_\_ Group No.: \_\_\_\_\_

Insurance No. 2: \_\_\_\_\_ Group No. 2: \_\_\_\_\_

Allergies: \_\_\_\_\_

Blood Type: \_\_\_\_\_

In case of emergency please contact: \_\_\_\_\_

**PROFESSIONAL HEALTH CARE PROVIDERS**

Primary Care Physician: \_\_\_\_\_

Cardiologist: \_\_\_\_\_

Pharmacy: \_\_\_\_\_

Neurologist: \_\_\_\_\_

Ophthalmologist: \_\_\_\_\_

Lab: \_\_\_\_\_

Nephrologist/Urologist: \_\_\_\_\_

Dermatologist: \_\_\_\_\_

Other: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_





# developmental milestones

## DEVELOPMENTAL MILESTONES

*(First-time occurrences):*

Focused eyes: \_\_\_\_\_

Rolled over in one direction: \_\_\_\_\_

Rolled over in other direction: \_\_\_\_\_

Smiled: \_\_\_\_\_

Slept through the night: \_\_\_\_\_

Laughed out loud: \_\_\_\_\_

Grabbed for something (toy, etc.): \_\_\_\_\_

Held own bottle: \_\_\_\_\_

Ate solid food: \_\_\_\_\_

Any food sensitivities or allergies: \_\_\_\_\_

Recognized own name: \_\_\_\_\_

Waved bye-bye: \_\_\_\_\_

Sat up: \_\_\_\_\_

Crawled: \_\_\_\_\_

Stood up holding on: \_\_\_\_\_

Stood up unassisted: \_\_\_\_\_

Cruised holding on: \_\_\_\_\_

Took first unassisted step: \_\_\_\_\_

Walked unassisted: \_\_\_\_\_

Ran: \_\_\_\_\_

Jumped: \_\_\_\_\_

Stood on one foot: \_\_\_\_\_

Hopped on one foot: \_\_\_\_\_

Climbed: \_\_\_\_\_

Crawled up stairs: \_\_\_\_\_

Walked up stairs: \_\_\_\_\_

Pedaled tricycle/bicycle: \_\_\_\_\_

Used a spoon: \_\_\_\_\_

Drank from a sippy cup: \_\_\_\_\_

Drank from a regular cup: \_\_\_\_\_

First babbled: \_\_\_\_\_

First spoke single word: \_\_\_\_\_

Spoke two words together: \_\_\_\_\_

Spoke full sentence: \_\_\_\_\_

Toilet trained daytime: \_\_\_\_\_

Toilet trained nighttime: \_\_\_\_\_

First cut a tooth: \_\_\_\_\_



































