

# Introduction

This book is for you.

This book is for you if you want to learn about *dysautonomias*. *Dysautonomias* are disorders of the *autonomic nervous system*, the “automatic nervous system” that regulates many body functions unconsciously, continuously, and dynamically, in everybody.

Dysautonomias are disorders of  
“automatic” body functions.

We wrote this book for patients with *dysautonomias*, for their families and caretakers, for their doctors, and for others who seek a source of information about these disorders.

*Dysautonomias* range from occasional annoying sensations in otherwise healthy people to progressive, debilitating diseases. They occur in all age groups. Some are established diseases, with changes in body tissues that a pathologist can see. Some are functional disorders, with chemical or biological changes that a clinical investigator can measure. Some are mysterious and controversial, because of a lack of accepted objective tests and

treatments. Some are rare and others common, but all involve more than one body function, and all have an impact on the sense of well-being. All involve multiple disciplines in medicine—cardiology, neurology, endocrinology, physical medicine, psychiatry. Predictably, relatively few cardiologists, neurologists, endocrinologists, rehabilitation medicine specialists, or psychiatrists feel comfortable in diagnosing *dysautonomias* or managing the patients.

Three factors have made the area of *dysautonomias* especially difficult.

The field of *dysautonomias* is difficult, because it is

- Multi-Disciplinary
- Integrative
- Mind-Body

First, the disorders are multi-disciplinary. Patients often cannot be served by specialists certified in programs in single disciplines. So one factor has been inadequate curriculum in medical schools and specialty training. Also because of the multi-disciplinary nature of *dysautonomias*, scientific peer-review committees tend to view as somewhat foreign applications for research funding and assign relatively low priority scores to the grant applications. So because of the structure of

scientific review procedures, scientific research has in several ways lagged behind.

Second, the disorders are integrative. Many factors determine levels of pulse rate, blood pressure, body metabolism, pain, fatigue, and the sense of psychological well-being. These factors interact with each other, and they change over time, depending on development and circumstances of life, and they are themselves regulated as parts of complex feedback systems. Scientific theories have lagged behind, in terms taking into account this complexity.

Third—and this is where the book you are now reading comes in—*dysautonomias* are often “mind-body” disorders. Scientific theories have also lagged behind, by continuing the old philosophical distinction between physical and mental body processes. We do not believe that this is the way the body actually works, and so we do not believe that *dysautonomias* or the patients suffering with them should be classified as “medical” or “psychiatric.” A major purpose of this book is educational, to teach to clinicians and patients, again and again, that the many symptoms of *dysautonomias* reflect real biological or chemical changes. When clinicians cannot identify the causes of the symptoms, that ignorance should not lead to dismissing the patients as having a psychiatric rather than a “real” problem.

This book has two main sections. The first section is about what *dysautonomias* are, from the point of view of medical scientific information about normal and

abnormal functions of the “automatic nervous system,” diagnoses, tests, and treatments. The second section is about living with *dysautonomias*. The section emphasizes that the disorders vary greatly, the individuals suffering from them differ greatly, seemingly routine activities of daily life can produce sometimes remarkable changes in “automatic” body functions, emotional distress interacts with the disorders to produce predictable effects, treatments can have limited benefits and important side effects, and the disorders pose numerous challenges to life at home and productivity at work.

### Sections of this book:

- What are *Dysautonomias*?
- Living with *Dysautonomias*

We recognize that this book will have several audiences, with very different abilities to digest the medical scientific information. This is why the book includes a large glossary of terms, with words in the text that are in italics listed in the glossary. The figures and figure legends are designed to provide a parallel text that is simpler than the main text. Each section includes text boxes, listing briefly the key points.

This book is a first attempt, and we expect it will need to be re-written repeatedly, as we receive feedback from you about its strengths and weaknesses, errors and

omissions. We need to hear from you, to make sure that this book really is for you.

Let us hear from you!

You can reach the NDRF  
website at [www.NDRF.org](http://www.NDRF.org).

