Cerebral palsy is a lifelong condition that affects the individual, family, and immediate community. Therefore, the goal of allowing the individual with cerebral palsy to live life with the least impact of the disability requires complex attention to the individual and the family. Furthermore, society needs to be sensitive and to accommodate individuals with disabilities by limiting architectural impediments and providing accessible public transportation and communication. The educational system provides the key means for helping the individual prepare to function in society to his or her maximum ability. In many ways, the medical care system probably has the least significant role in preparing the child with cerebral palsy to function optimally in society. However, the medical care system is the place where parents first learn that their child has developmental issues outside the expected norm. It is almost universally the place where parents also expect the child to be made normal in our modern society. In earlier times, the parents would expect healing to possibly come from the doctor, but also they would place hope for healing in religion. As this belief in spiritual or miraculous healing has decreased, a significant font of hope has decreased for parents of young children with disabilities.

The text aims to help the child with cerebral palsy to develop into an adult in whom the effects of the disability are managed so that they have the least impact possible on adult function. This intention is in the context of the fact that the magnitude of improvement in the disability that occurs with ideal management of the musculoskeletal system during growth may be only a small improvement. Probably the more significant aspect of good musculoskeletal management through childhood is helping the child and family to maintain realistic hope for the successful adult life of the growing child. This aim requires the medical practitioner to get to know the child and family and to communicate in a compassionate way realistic expectations of the child’s function. For many reasons, the greatest difficulty in providing this kind of care is the limited time practitioners have to spend with the individual patient. There is also the sense, especially among orthopedic physicians, that cerebral palsy cannot be cured (cannot make the child function normally), and thus it is a frustrating condition with which to work. The physician must maintain a balance between communicating hopelessness to the patient and family; and feeling the need to do something, usually a heel cord lengthening, because the parents are frustrated that the child is not progressing. All medical decisions, including a surgical option, should always consider both the short- and long-term impact. With every decision the medical practitioner should ask, “What will be the impact of this recommendation by the time the child is a mature adult?” This is the most difficult perspective, especially
for young practitioners with little experience. This text is intended to pro-
vide this insight as much as possible.

Another issue is the poor scientific documentation of natural history and
treatment response in cerebral palsy, which has become clearer to me in the
course of writing this book. With little scientifically based natural history
and few long-term studies, much of what is written in this text is expert-
based observation. The goal of writing this is not to say that it is absolute
fact, but to provide the starting point of gathering information with the hope
that others will be stimulated to ask questions and pursue research to prove
or disprove the concepts.

The research, which is of help in treating children with cerebral palsy,
needs to be planned and evaluated with consideration of its long-term im-
 pact on the child’s growth and development. All treatment should also con-
sider the negative impact on the child. As an example, a number of moder-
ately good studies have analyzed the impact of wearing ankle orthotics on
the young child. Although the orthotics may provide an immediate benefit
by improving the child’s gait, there is probably no long-term benefit. Thus,
if the child develops a strong sense of opposition to wearing the brace at 10
years of age because of peer pressure, the brace wear cannot be justified on
a cost–benefit analysis.

It is also important to consider the quality of the scientific evidence, rang-
ing from double-blinded protocols to case reports, but it is equally important
not to get hung up on this being the final answer. For example, excellent
double-blinded studies show that botulinum toxin decreases spasticity and
improves gait for a number of months. Therefore, these studies need to be con-
sidered in the context of our goal, which is to give the child the maximum
possible function at full maturity. Because no evidence currently suggests that
botulinum has either a negative or a positive effect on this long-term goal, the
family and physician should decide together if botulinum injection has a pos-
itive cost–benefit ratio, as its effects will last only for approximately 6 months.
In comparison, no double-blind studies show that Achilles tendon lengthen-
ings improve gait three or six months after the surgery, and no such studies
are needed because the goal of surgery is to make an improvement in gait
several years later and to have improvement at maturity. Most important is
that surgery create no disability at maturity. From this perspective, it would
be much more useful to have a good controlled case series with a 15-year
follow-up than a double-blinded study with six months follow-up.

This book should stimulate research that will improve the knowledge base
which is focused on the long-term outcome of treatments. However, just be-
cause the scientific knowledge base is poor does not mean that we should not
apply the best knowledge available to current patients. In addition to research,
an individual professional can best extend his or her knowledge base through
personal experience. This means that the child and family should be followed
over time by the same practitioner with good documentation. By far, my best
source of information has been the children whom I have followed for 10 to
20 years with videotapes every year or two. Practitioner experience is ex-
tremely important for augmenting the relatively poor scientific knowledge
base for musculoskeletal treatment. Careful ongoing follow-up is also crucial
to providing hope for the families and the individuals with cerebral palsy.

How to Use This Text and CD

The text of Cerebral Palsy is set up in three sections, with the first section
containing 11 chapters that deal with specific aspects of cerebral palsy from
the perspective of managing the motor impairment. The first four chapters address primarily global issues of the child and family. The fifth chapter provides an overview of the medical and community care system and philosophy. The sixth chapter addresses the myriad options of equipment encountered in the treatment of the musculoskeletal impairment, and the seventh addresses the problems related to gait. The last four chapters are related to problems encountered in anatomical regions. These chapters also include management of the deformities and management of complications of medical treatment. These chapters are followed by treatment algorithms relevant to the issues discussed within the chapter. Also included in the chapters are patient case examples. Many of the case examples have videos and are designated by a video symbol. Each case has a unique name assigned to the patient and the video is accessed by opening the CD followed by opening the movies section, then opening the video with the same name. The second section of the book includes descriptions of techniques in rehabilitation often used with children with cerebral palsy. The third section is a surgical atlas with the procedures organized by anatomical area.

The CD included with this text is opened with a Web browser. Because the data on the CD is coded with XML and JAVA, only browsers released after 2002, such as Netscape 7.0, Explorer 6.0 or Safari, will be fully able to access this data. Some of the text in the book is organized in topics and is displayed in the section entitled “Main.” All references on the CD have the abstract available on the CD by activating the link associated with the reference. Cases can also be activated from these references in the Main section. There is also a section called “Cases,” which lists all the cases by name as listed in the text of the book. Following these cases are short quiz questions, which can be used to test understanding or study the material on line. There is also a section called “Quizzes,” which lists the quizzes by name of the cases. These quizzes can be opened and answered referring to the full case descriptions. The answers from the quizzes will be tabulated to keep a running total of correct answers for each session. After a quiz is accessed, it will also change color to remind the reader that he has already reviewed that quiz. The section entitled “Decision Trees” is the treatment algorithms, which are present at the end of each chapter in the book. These decision trees are set up so that area of interest is linked to the text in “Main” for further reading. The section called “Search” is an electronic index to search for specific subjects with in the chapter of the section “Main.” Because of space limitations, only individual chapters can be searched at one time. So if you want to search for “crutches,” you first should activate the Durable Medical Goods chapter, and then search. The results of the search allow you to directly link to the area of interest. The section “History” keeps a running history of the areas that have been assessed, so if you want to return to an area you were reading earlier in the session you can open the history and it will allow you to return to that area. The section “About” includes information on the use of the CD and acknowledgments.

In summary, the CD includes videos, case study quizzes, and reference abstracts, which are not included in the book. The book includes significant portions of text not included on the CD, sections on rehabilitation techniques, and a surgical atlas. The book and the CD are intended to complement each other but each can also be used alone.

Acknowledgments

The production of this book and CD was only possible because of an extensive network of support that was available to me. The support of the
administration of the Nemours Foundation, especially the support of Roy Proujansky and J. Richard Bowen in giving me time to work on this project was crucial. It was only through the generous support in caring for my patients by my partners and staff, Kirk Dabney, Suken Shah, Peter Gabos, Linda Duffy, and Marilyn Boos, that I was able to dedicate time to writing. I am very grateful for the generous material provided by all the contributors and for the extensive and extremely important role of the feedback given to me by the consultants. In spite of having an extremely busy practice, Kirk Dabney still found time to read all of the first section, making very valuable improvements, and writing major sections of the upper extremity chapter. With his wide experience, Michael Alexander made an excellent contribution in the editorial support of the section on rehabilitation. The task of writing and editing would have been impossible without the dedicated work of Kim Eissmann, Linda Donahue, and Lois Miller. Production of the CD involved a significant amount of detailed editing and HTML coding, most of which was performed by Linda Donahue. To add a personal touch to the cases, a unique name was assigned by Lois Miller. The CD required a great effort of technical programming to make it work intuitively on all computer formats. Tim Niiler patiently persisted with this frustrating task until it all worked. Videos were masked and formatted by Robert DiLorio. Production of the graphics was a major effort in understanding the complex material in which Erin Browne excelled. This production would have been impossible without her dedication to understanding the concepts and bringing them to visual clarity. I would also like to thank the staff of Chernow Editorial Services, especially Barbara Chernow. Without the long support through out the evolution of this book by Robert Albano and his staff at Springer, this project would also have been much more difficult. And finally, I am most grateful for the many families and children who have allowed me to learn from them what it is like to live with the many different levels of motor impairments. It is to the families and children that I dedicate this work in the hope that it will lead to improved care and understanding by medical professionals.

Freeman Miller, MD
Cerebral Palsy
Miller, F.