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The Official Parents Sourcebook On Krabb Disease Revised Pb 2003

James N. Parker, Philip M. Parker



The Official Parents Sourcebook On Krabbe Disease Revised Pb 2003:

An Inside Look at Krabbe Disease from Diagnosis Through Treatment: What Families and Health Professionals in New York State Need to Know Jessica L. Vega,2007 This research addresses emerging issues families and health care professionals may face as newborn screening for Krabbe disease commences It is designed to document what the parent experience has been prior to newborn screening and assess how that experience is likely to be altered

The Official Parent's Sourcebook on Lesch-Nyhan Syndrome Icon Health Publications,2005-01-01 This book has been created for parents who have decided to make education and research an integral part of the treatment process Although it also gives information useful to doctors caregivers and other health professionals it tells parents where and how to look for information covering virtually all topics related to lesch nyhan syndrome also Hereditary Hyperuricemia and Chorea of the Hand Syndrome HG PRT deficiency syndrome HGPRT Absence of HPRT Absence of Hyperuricemia Chorea of the Hand Self mutilation Syndrome Hyperuricemia Oligophrenia from the essentials to the most advanced areas of research The title of this book includes the word official This reflects the fact that the sourcebook draws from public academic government and peer reviewed research Selected readings from various agencies are reproduced to give you some of the latest official information available to date on lesch nyhan syndrome Given parents increasing sophistication in using the Internet abundant references to reliable Internet based resources are provided throughout this sourcebook Where possible guidance is provided on how to obtain free of charge primary research results as well as more detailed information via the Internet E book and electronic versions of this sourcebook are fully interactive with each of the Internet sites mentioned clicking on a hyperlink automatically opens your browser to the site indicated Hard copy users of this sourcebook can type cited Web addresses directly into their browsers to obtain access to the corresponding sites In addition to extensive references accessible via the Internet chapters include glossaries of technical or uncommon terms

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