Understanding Rett Syndrome

A Practical Guide for Parents, Teachers, and Therapists

2nd revised edition
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A Practical Guide for Parents, Teachers, and Therapists

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Foreword

Rett Syndrome: A Survey of Psychological and Educational Experiences in Sweden

In this volume, with great devotion and impact, Barbro Lindberg presents the clinical picture and treatment modalities of Rett syndrome. The disorder was first described more than 30 years ago. However, only through the incredible activities undertaken by Kathy Hunter in the United States has it received such unusually widespread international attention.

Described here is a clinical syndrome that has now been diagnosed in more than 31 countries, and the extent to which the picture is everywhere consistent, is nothing less than remarkable. This is a disorder found exclusively in girls, presenting a particular characterization of neurological symptoms. Today research is being conducted worldwide in search of its cause.

Barbro Lindberg’s special involvement has been in the day-to-day lives of these girls and women. Having studied the roles of their parents and guardians, she presents her data and discussion with painstaking exactness and detail.

This monograph affords a very empathetic view of the situation these parents are in and will certainly be a help in enabling coping with such a difficult chronic situation that concerns not just the mother, but the entire family.

I hope this book will be widely disseminated. The reader should note that it offers valuable help with regard to the social, physical, and ethical aspects of dealing with a most difficult congenital disorder.

Summer 1991

Andreas Rett, M. D.
This report was written to be the book I would have liked to have had when a girl with Rett syndrome was placed in my class at a time when I had no knowledge or experience of the disorder. This student of mine, and my feeling of inadequacy for her, incited me to find out more about the syndrome. I realized that I had to really understand her acting in order to understand how to act myself.

This book is primarily intended for people close to those with Rett syndrome; parents and professionals who are trying to make everyday life easier and better for them. It is based on a study of Swedish females, but the conclusions are general and valid to all those with classical Rett syndrome, and so I hope that this English version will find many new readers, and that it will provide an answer to some of the questions you may have.

I want to thank Professor Andreas Rett for his generosity and interest in the translation of the book, and Dr. Mary Murphy, members of the IRSA, and many good friends who helped me with the translation, corrected me, and made the language more enjoyable. And my special thanks to Kathy Hunter, for all her support and understanding.

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Barbro Lindberg