

RAISING THE GODDESS OF SPRING

A Guide for Parents Raising Children with Rare Chromosome Disorders

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Foreword by Dr. Beverly Searle, CEO of Unique, The Rare Chromosome & Gene Disorder Support Group

Publication Fact Sheet

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Turn to this book for guidance and support for parents raising children with rare chromosome disorders. Learn about:

- Chromosomes, chromosome disorders, and why they happen;
- Experiences surrounding diagnosis and finding information and support;
- Researching, advocacy and partnering with professionals;
- Common medical and developmental concerns;
- Managing day-to-day, practical advice and building resilience;
- Emergency and extended hospitalizations;
- Reproductive considerations for carriers of chromosome difference;
- Changes to relationships with others;
- Using humour and managing your mental health;
- Planning for the future, respite care, experiencing child loss and more.

The authors combine a wealth of experience in parenting, advocacy, mental health, special education, estates and benefits, clinical genetics, and child development and are all involved with the parent support organization Chromosome 22 Central (www.c22c.org). The book also includes the voices of other parents.

This book will be of interest to parents of children who have rare chromosome disorders, as well as physicians, nurses, genetic counsellors, developmental therapists, special education teachers, or anyone who is involved in the care and support of children with rare chromosome disorders.

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