

WE HELP KIDS AND FAMILIES  
BE THEIR HEALTHIEST



## RETT SYNDROME / LE SYNDROME DE RETT

*Kaitlin Atkinson Family Resource Library / Bibliothèque de  
ressources familiales Kaitlin Atkinson*

*Resource List / Ressources*



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**Building bridges through sensory integration: therapy for children with autism and other pervasive developmental disorders** / Yack, Ellen. -- Arlington, TX: Future Horizons Inc., 2002.

*Written by three occupational therapists, this book offers a combination of theory and strategies. It is a useful tool for those working with young children, but also broad enough to be adapted for older children and adults.*

FAM RJ 496 .S44 Y34 2002

**Educational and therapeutic intervention in Rett syndrome** -- Clinton, MD: International Rett Syndrome Assoc. 1995.

FAM RJ 506 .R47 E38

**Keeping Katherine: a mother's journey to acceptance** / Zimmermann, Susan -- New York: Three Rivers Press, 2004.

*A story of personal transformation that reminds us that it isn't what happens to us that shapes our humanity, but how we react, Keeping Katherine shows the unconditional love that exists in families and the gifts the profoundly disabled can offer to those who try to understand them.*

FAM HQ 759.913 .Z56 2004

**Pathways to learning in Rett syndrome** / Lewis, J.E. -- London: Rett Syndrome Association (U.K.) 1996.

*Parents and teachers of girls with Rett Syndrome will welcome this book, which offers a greater understanding of, and insight into, their potential to learn and develop.*

FAM RJ 506 .R47 L48

**The Rett syndrome handbook** / Hunter, Kathy -- Clinton, Maryland: International Rett Syndrome Association, 2007.

*A complete and comprehensive resource dealing with all facets of Rett Syndrome in words you can understand from those who understand. A valued resource, now expanded and revised in this second edition.*

FAM RJ 506 .R47 H86 2006

**Understanding Rett syndrome: a practical guide for parents, teachers, and therapists** / Lindberg, Barbro -- Toronto: Hogrefe & Huber, 2006.

*This book describes the difficulties and challenges of girls and women with Rett Syndrome. It proposes solutions to help them in everyday life with regards to social, physical and ethical aspects.*

FAM RJ 506 .R47 L56 2006

**Web sites / Sites internet**

Ontario Rett Syndrome Association

[www.rett.ca/](http://www.rett.ca/)

Rett Syndrome – CHEO / Syndrome de Rett - CHEO

<http://www.cheo.on.ca/en/rett>

International Rett Syndrome Association

<http://rettsyndrome.org>

Rett Syndrome – MedlinePlus from the U.S. National Library of Medicine

<http://www.nlm.nih.gov/medlineplus/rettsyndrome.html>



Rett Syndrome Research Trust  
<http://www.rst.org/>

Rett Syndrome Information Page – From the National Institute of Neurological Disorders and Stroke  
<https://www.ninds.nih.gov/Disorders/All-Disorders/Rett-Syndrome-Information-Page>

Association québécoise du syndrome de Rett  
<https://www.rettqc.org/>

Rett Syndrome – NORD: National Organization for Rare Disorders  
<http://rarediseases.org/rare-diseases/rett-syndrome/>

### **Local Contacts / Liaison régionales**

Ontario Rett Syndrome Association  
PO Box 50030  
London, ON N6A 6H8  
519-474-8677  
[www.rett.ca](http://www.rett.ca)  
[info@rett.ca](mailto:info@rett.ca)

Association québécoise du syndrome de Rett  
903, boulevard LaFayette  
Longueuil, Québec J4K 3A8  
514-585-2740  
<https://www.rettqc.org/>  
[info@rettqc.org](mailto:info@rettqc.org)

CHEO  
401 Smyth Rd.  
Ottawa, ON K1H 8L1  
Physician Referral Required  
613-737-7600

*This guide provides medical material for information purposes only and is not intended to replace the advice of your physician. The information may not always apply to your individual situation.*

*The guide represents material available in the Family Resource Library collection at CHEO. It is not intended to be an exhaustive list. Your local public library may also be able to provide you with information.*

*If you require materials in alternative formats, please contact the library at 613-737-7600 ext. 2157 or at [library@cheo.on.ca](mailto:library@cheo.on.ca).*

*Ce guide fournit du matériel médical pour informations seulement et ne vise pas à remplacer les conseils du médecin. Ces informations pourraient ne pas toujours s'appliquer aux situations individuelles.*

*Ce guide présente le matériel disponible à la bibliothèque de ressources familiales du CHEO. Ce n'est pas une liste complète. Votre bibliothèque publique locale pourrait aussi être en mesure de vous fournir des informations précieuses.*

*Si vous avez besoin des documents en formats alternatifs, s'il vous plaît contacter la bibliothèque au 613-737-7600 poste 2157 ou à [library@cheo.on.ca](mailto:library@cheo.on.ca).*

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