

**INTERESTING ENDOCRINE LINKS FOR PATIENTS AND FAMILIES**  
**ENDOCRINOLOGY & DIABETES UNIT HOMEPAGE: <<http://endodiab.bcchildrens.ca>>**

**General endocrine / Medical**

[www.endocrineweb.com](http://www.endocrineweb.com)  
[www.endocrineonline.org](http://www.endocrineonline.org)  
[www.phac-aspc.gc.ca/chn-rcs/index-eng.php](http://www.phac-aspc.gc.ca/chn-rcs/index-eng.php)  
[www.hormone.org](http://www.hormone.org)  
[www.eurospe.org/patient/English/index.html](http://www.eurospe.org/patient/English/index.html)  
[www.healthlinkbc.ca](http://www.healthlinkbc.ca)  
[www.health.gov.bc.ca/insurance](http://www.health.gov.bc.ca/insurance)  
[www.nlm.nih.gov/medlineplus/endocrinesystem.html](http://www.nlm.nih.gov/medlineplus/endocrinesystem.html)  
[www.drugwatch.com](http://www.drugwatch.com)

Endocrine Web  
Endocrine Online  
Public Health Agency of Canada  
The Hormone Foundation  
European Society for Pædiatric Endocrinology: English-language handouts  
HealthLink BC  
Health Insurance BC  
MEDLINEplus Health Information: Endocrine System  
DrugWatch.com

**Growth disorders**

[www.hgfound.org](http://www.hgfound.org)  
[www.hgfound.org/pub\\_patterns.html](http://www.hgfound.org/pub_patterns.html)  
[www.hgfound.org/res\\_disorders.html](http://www.hgfound.org/res_disorders.html)  
[www.hgfound.org/pub\\_growth.html](http://www.hgfound.org/pub_growth.html)  
[www.hgfound.org/res\\_adultsgrowthhormone.html](http://www.hgfound.org/res_adultsgrowthhormone.html)  
[www.lpaonline.org](http://www.lpaonline.org)  
[www.hormone.org/growth](http://www.hormone.org/growth)  
[www.magicfoundation.org](http://www.magicfoundation.org)  
[www.magicfoundation.org/www/docs/108](http://www.magicfoundation.org/www/docs/108)  
[www.magicfoundation.org/www/docs/105](http://www.magicfoundation.org/www/docs/105)  
[www.magicfoundation.org/www/docs/10.1066](http://www.magicfoundation.org/www/docs/10.1066)  
[www.magicfoundation.org/www/docs/108.1020](http://www.magicfoundation.org/www/docs/108.1020)  
[www.magicfoundation.org/www/docs/176](http://www.magicfoundation.org/www/docs/176)  
[www.magicfoundation.org/www/docs/108.897](http://www.magicfoundation.org/www/docs/108.897)  
[www.magicfoundation.org/www/docs/11.1404](http://www.magicfoundation.org/www/docs/11.1404)  
[www.magicfoundation.org/www/docs/978.1035](http://www.magicfoundation.org/www/docs/978.1035)  
[www.magicfoundation.org/www/docs/101.1060](http://www.magicfoundation.org/www/docs/101.1060)  
[www.magicfoundation.org/www/docs/108.24](http://www.magicfoundation.org/www/docs/108.24)  
[www.magicfoundation.org/www/docs/106](http://www.magicfoundation.org/www/docs/106)  
[www.magicfoundation.org/www/docs/113.1518](http://www.magicfoundation.org/www/docs/113.1518)  
[www.magicfoundation.org/www/docs/985.803](http://www.magicfoundation.org/www/docs/985.803)  
[www.nutropin.ca](http://www.nutropin.ca)  
[www.herewegrow.ca](http://www.herewegrow.ca)  
[www.nutropin.com](http://www.nutropin.com)

The Human Growth Foundation  
*Patterns of Growth Disorders of Growth*  
*Pediatric Growth Hormone Deficiency*  
*Adult Growth Hormone Deficiency*  
Little People of America  
The Hormone Foundation: *Growth Disorders*  
The MAGIC Foundation  
*Childhood Growth Hormone Deficiency—General Information*  
*Adult Growth Hormone Deficiency—General Information*  
*Constitutional Growth Delay in Children*  
*Growth Hormone Therapy—Questions*  
*Failure to Thrive*  
*Children's Growth Abnormalities—An Overview*  
*Idiopathic Short Stature*  
*IGF-1 Deficiency*  
*Psychosocial Issues of Growth-Delayed Children*  
*Dental Problems Associated with Growth Hormone Deficiency*  
*Failure to Grow in Chronic Kidney Disease*  
*Small for Gestational Age—General Information*  
*Intrauterine Growth Retardation*  
Roche Canada: Nutropin® information  
*Here We Grow*  
Genentech USA (Nutropin®): Growth Hormone Site

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[www.emdserono.ca/en/therapeutic\\_areas/endocrinology/endocrinology.html](http://www.emdserono.ca/en/therapeutic_areas/endocrinology/endocrinology.html)  
[www.saizenus.com](http://www.saizenus.com)  
[www.justgrowth.com](http://www.justgrowth.com)  
[www.lilly.ca](http://www.lilly.ca)  
[www.humatrope.com](http://www.humatrope.com)  
[www.omnitrope.ca](http://www.omnitrope.ca)  
[www.omnitrope.com](http://www.omnitrope.com)

EMD Serono Canada (Saizen®): Growth Therapies  
EMD Serono USA (Saizen®)  
*JustGrowth*  
Eli Lilly Canada (Humatrope®)  
Eli Lilly USA: Humatrope®  
Sandoz Canada: Omnitrope®  
Sandoz USA: Omnitrope®

**Thyroid disorders**

[www.thyroid.ca](http://www.thyroid.ca)  
[www.ngdf.org](http://www.ngdf.org)  
[www.allthyroid.org](http://www.allthyroid.org)  
[www.thyroidcancercanada.org](http://www.thyroidcancercanada.org)  
[www.thyca.org](http://www.thyca.org)  
[www.checkyourneck.com](http://www.checkyourneck.com)  
[www.thyroid.org](http://www.thyroid.org)  
[www.eurothyroid.com](http://www.eurothyroid.com)  
[www.thyroid-fed.org](http://www.thyroid-fed.org)  
[www.magicfoundation.org](http://www.magicfoundation.org)  
[www.magicfoundation.org/www/docs/114.125](http://www.magicfoundation.org/www/docs/114.125)  
[www.magicfoundation.org/www/docs/114.126](http://www.magicfoundation.org/www/docs/114.126)  
[endocrine.niddk.nih.gov/pubs/hypothyroidism/index.aspx](http://endocrine.niddk.nih.gov/pubs/hypothyroidism/index.aspx)  
[endocrine.niddk.nih.gov/pubs/hyperthyroidism/index.aspx](http://endocrine.niddk.nih.gov/pubs/hyperthyroidism/index.aspx)  
[www.dshs.state.tx.us/newborn/infant.shtm](http://www.dshs.state.tx.us/newborn/infant.shtm)  
[www.hormone.org/thyroid](http://www.hormone.org/thyroid)  
[www.thyrolink.com](http://www.thyrolink.com)  
[www.mythyroid.com](http://www.mythyroid.com)  
[www.endocrineweb.com/conditions/thyroid/your-thyroid-gland](http://www.endocrineweb.com/conditions/thyroid/your-thyroid-gland)  
[health.groups.yahoo.com/group/ThyroidPatientsCanada](http://health.groups.yahoo.com/group/ThyroidPatientsCanada)

The Thyroid Foundation of Canada  
The National Graves Disease Foundation  
The Thyroid Foundation of America  
Thyroid Cancer Canada  
Thyroid Cancer Survivors' Association  
Light of Light Foundation  
The American Thyroid Association  
European Thyroid Association  
Thyroid Federation International  
The MAGIC Foundation  
*Congenital Hypothyroidism—General Information*  
*Clinical Hypothyroidism—General Information*  
NIDDK Patient Information: *Hypothyroidism*  
NIDDK Patient Information: *Hyperthyroidism*  
*Hypothyroidism and Your Infant* (Texas)  
The Hormone Foundation: *Thyroid Disorders*  
ThyroLink (commercial site from Merck & Co.)  
MyThyroid.com  
Endocrine Web Thyroid links  
Thyroid Patients Canada (Yahoo group)

**Adrenal disorders**

[www.nadf.us](http://www.nadf.us)  
[www.magicfoundation.org/www/docs/100](http://www.magicfoundation.org/www/docs/100)  
[www.familyvillage.wisc.edu/lib\\_adrh.htm](http://www.familyvillage.wisc.edu/lib_adrh.htm)  
[www.cc.nih.gov/ccc/patient\\_education/pepubs/cah.pdf](http://www.cc.nih.gov/ccc/patient_education/pepubs/cah.pdf)  
[pediatrics.aappublications.org/content/106/6/1511.full.pdf](http://pediatrics.aappublications.org/content/106/6/1511.full.pdf)  
[www.rch.org.au/cah\\_book/index.cfm?doc\\_id=1375](http://www.rch.org.au/cah_book/index.cfm?doc_id=1375)  
[www.rch.org.au/emplibrary/cah\\_book/CAH.pdf](http://www.rch.org.au/emplibrary/cah_book/CAH.pdf)

The National Adrenal Diseases Foundation  
The MAGIC Foundation: *Congenital Adrenal Hyperplasia—General Information*  
Family Village Factsheet: *Congenital Adrenal Hyperplasia*  
NIH Patient Information: *Facts about Congenital Adrenal Hyperplasia*  
AAP Technical Report: *Congenital Adrenal Hyperplasia*  
*Your Child with Congenital Adrenal Hyperplasia* (Dr. Gary Warne)  
French version

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[www.rch.org.au/emplibrary/cah\\_book/YourChildWithCAHVNesepdf.pdf](http://www.rch.org.au/emplibrary/cah_book/YourChildWithCAHVNesepdf.pdf) Vietnamese version  
[www.rch.org.au/emplibrary/cah\\_book/YourChildwithCongenitalAdrenalHyperplasiaChinese.pdf](http://www.rch.org.au/emplibrary/cah_book/YourChildwithCongenitalAdrenalHyperplasiaChinese.pdf) Chinese version  
[www.hopkinschildrens.org/cah](http://www.hopkinschildrens.org/cah) *Congenital Adrenal Hyperplasia Due to 21-Hydroxylase Deficiency: A Guide for Patients and Their Families* (Johns Hopkins)  
[www.hopkinschildrens.org/cah/printable.html](http://www.hopkinschildrens.org/cah/printable.html) Printer-friendly format  
[www.ahn.org.uk](http://www.ahn.org.uk) Adrenal Hyperplasia Network (UK)  
[www.endocrineonline.org/cah.htm](http://www.endocrineonline.org/cah.htm) Endocrine Online: *Congenital Adrenal Hyperplasia*  
[www.endocrineonline.org/pdf%20box/cah.pdf](http://www.endocrineonline.org/pdf%20box/cah.pdf) *Congenital Adrenal Hyperplasia: Information for Adults*  
[www.livingwithcah.com](http://www.livingwithcah.com) Climb Congenital Adrenal Hyperplasia UK Support Group  
[www.cah.org.au](http://www.cah.org.au) Congenital Adrenal Hyperplasia Support Group (Australia)  
[www.congenitaladrenalhyperplasia.org](http://www.congenitaladrenalhyperplasia.org) Congenital Adrenal Hyperplasia Family Support and Education Network  
[www.caresfoundation.org](http://www.caresfoundation.org) CARES (Congenital Adrenal Hyperplasia Research, Education and Support) Foundation  
[www.dshs.state.tx.us/newborn/hand\\_cah.shtm](http://www.dshs.state.tx.us/newborn/hand_cah.shtm) *Congenital Adrenal Hyperplasia: A Handbook for Parents* (Texas)  
[endocrine.niddk.nih.gov/pubs/cushings/cushings.aspx](http://endocrine.niddk.nih.gov/pubs/cushings/cushings.aspx) NIDDK Patient Information: *Cushing's Syndrome*  
[www.nichd.nih.gov/health/topics/cushingssyndrome.cfm](http://www.nichd.nih.gov/health/topics/cushingssyndrome.cfm) NICHD Patient Information: *Cushing Syndrome*  
[www.csrf.net](http://www.csrf.net) Cushing's Support and Research Foundation  
[www.nvacp.nl](http://www.nvacp.nl) Addison and Cushing International Foundation  
[www.addisonsociety.ca](http://www.addisonsociety.ca) Canadian Addison Society  
[www.addisons.org.uk](http://www.addisons.org.uk) Addison's Disease Self-Help Group (UK)  
[www.addisons.org.uk/info/manual/adshgguidelines.pdf](http://www.addisons.org.uk/info/manual/adshgguidelines.pdf) *Addison's Disease Owner's Manual*  
[www.addisons.org.uk/info/manual/parenting.pdf](http://www.addisons.org.uk/info/manual/parenting.pdf) *Being the Parent of a Child with Addison's*  
[endocrine.niddk.nih.gov/pubs/addison/addison.aspxhtm](http://endocrine.niddk.nih.gov/pubs/addison/addison.aspxhtm) NIDDK Patient Information: *Adrenal Insufficiency and Addison's Disease*  
[www.cc.nih.gov/ccc/patient\\_education/pepubs/mngadrins.pdf](http://www.cc.nih.gov/ccc/patient_education/pepubs/mngadrins.pdf) NIH Patient Information: *Managing Adrenal Insufficiency*  
[www.gosh.nhs.uk/gosh\\_families/information\\_sheets/cortisol\\_deficiency/cortisol\\_deficiency\\_families\\_booklet.pdf](http://www.gosh.nhs.uk/gosh_families/information_sheets/cortisol_deficiency/cortisol_deficiency_families_booklet.pdf)  
Institute of Child Health (UK): *Cortisol Deficiency and Steroid Replacement Therapy*  
[www.ulf.org](http://www.ulf.org) United Leukodystrophy Foundation  
[www.ninds.nih.gov/disorders/adrenoleukodystrophy/adrenoleukodystrophy.htm](http://www.ninds.nih.gov/disorders/adrenoleukodystrophy/adrenoleukodystrophy.htm) NINDS Patient Information on Adrenoleukodystrophy  
[www.adrenocorticalcarcinoma.org](http://www.adrenocorticalcarcinoma.org) Adrenal Cancer Support  
[www.endocrineweb.com/endocrinology/your-adrenal-glands](http://www.endocrineweb.com/endocrinology/your-adrenal-glands) Endocrine Web Adrenal Links

**Parathyroid disorders**

[endocrine.niddk.nih.gov/pubs/hyper/index.aspx](http://endocrine.niddk.nih.gov/pubs/hyper/index.aspx) NIDDK Patient Information: *Hyperparathyroidism*  
[www.paget.org/index.php/patients/primary-hyperparathyroidism.html](http://www.paget.org/index.php/patients/primary-hyperparathyroidism.html) The Paget Foundation: *Primary Hyperparathyroidism*  
[www.endocrineweb.com/conditions/parathyroid/your-parathyroid-glands](http://www.endocrineweb.com/conditions/parathyroid/your-parathyroid-glands) Endocrine Web Parathyroid Links  
[www.parathyroid.com](http://www.parathyroid.com) Parathyroid.com

**Diabetes insipidus / Histiocytosis**

[www.cc.nih.gov/ccc/patient\\_education/pepubs/di.pdf](http://www.cc.nih.gov/ccc/patient_education/pepubs/di.pdf) NIH Patient Information: *Diabetes Insipidus: What Kind of Diabetes is That?*  
[www.diabetesinsipidus.org](http://www.diabetesinsipidus.org) Diabetes Insipidus Foundation, Inc.

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[www.ndif.org](http://www.ndif.org)  
[www.histio.org](http://www.histio.org)  
[www.histiocytosis.ca](http://www.histiocytosis.ca)

Nephrogenic Diabetes Insipidus Foundation  
Histiocytosis Association of America  
Histiocytosis Association of Canada

**Pituitary and brain tumor disorders**

[www.magicfoundation.org/www/docs/110](http://www.magicfoundation.org/www/docs/110)  
[www.pituitary.org](http://www.pituitary.org)  
[www.pituitary.org.uk](http://www.pituitary.org.uk)  
[endocrine.niddk.nih.gov/pubs/prolact/prolact.aspx](http://endocrine.niddk.nih.gov/pubs/prolact/prolact.aspx)  
[endocrine.niddk.nih.gov/pubs/acro/acro.aspx](http://endocrine.niddk.nih.gov/pubs/acro/acro.aspx)  
[www.nichd.nih.gov/health/topics/pituitary\\_tumors\\_in\\_children.cfm](http://www.nichd.nih.gov/health/topics/pituitary_tumors_in_children.cfm)  
[www.hormone.org/pituitary](http://www.hormone.org/pituitary)

The MAGIC Foundation: *Panhypopituitarism—General Information*  
The Pituitary Tumor Network Association  
The Pituitary Foundation (UK)  
NIDDK Patient Information: *Prolactinoma*  
NIDDK Patient Information: *Acromegaly*  
NICHD Patient Information: *Pituitary Tumors in Children*  
The Hormone Foundation: *Pituitary Disorders*

**Septo-optic dysplasia / Optic nerve hypoplasia**

[www.magicfoundation.org](http://www.magicfoundation.org)  
[www.magicfoundation.org/www/docs/101.115](http://www.magicfoundation.org/www/docs/101.115)  
[www.magicfoundation.org/www/docs/101.116](http://www.magicfoundation.org/www/docs/101.116)  
[www.ninds.nih.gov/disorders/septo\\_optic\\_dysplasia/septo\\_optic\\_dysplasia.htm](http://www.ninds.nih.gov/disorders/septo_optic_dysplasia/septo_optic_dysplasia.htm)  
[focusfamilies.org/focus](http://focusfamilies.org/focus)  
[www.onesmallvoicefoundation.org](http://www.onesmallvoicefoundation.org)  
[www.onesmallvoicefoundation.org/pdf/ONH%20pamphlet\\_sm.pdf](http://www.onesmallvoicefoundation.org/pdf/ONH%20pamphlet_sm.pdf)

The MAGIC Foundation  
*Septo-Optic Dysplasia—General Information*  
*Optic Nerve Hypoplasia—General Information*  
NINDS Patient Information: *Septo-Optic Dysplasia*  
FOCUS: ONH/SOD Information, Education and Support  
One Small Voice Foundation  
*Optic Nerve Hypoplasia: A Guide for Families*

**Central precocious puberty**

[www.magicfoundation.org/www/docs/146](http://www.magicfoundation.org/www/docs/146)  
[pediatrics.aappublications.org/content/123/4/e752.full.pdf](http://pediatrics.aappublications.org/content/123/4/e752.full.pdf)  
[www.lupronped.com](http://www.lupronped.com)  
[bookstore.cw.bc.ca](http://bookstore.cw.bc.ca)  
[bookstore.cw.bc.ca](http://bookstore.cw.bc.ca)

The MAGIC Foundation: *Precocious Puberty—General Information*  
*Consensus Statement on the Use of Gonadotropin-Releasing Hormone Analogs in Children*  
*What Parents Should Know About Central Precocious Puberty* (Abbott Laboratories)  
*Early Puberty in Girls* (to order)  
*Puberté précoce chez la fille* (to order)

**Kallmann syndrome**

[www.hypohh.net](http://www.hypohh.net)  
[www.kallmanns.org](http://www.kallmanns.org)

HYP0HH (for hypogonadotropic hypogonadism)  
Kallmann Syndrome Organisation

**Polycystic ovary syndrome, hirsutism and premature ovarian failure**

[www.pcosupport.org](http://www.pcosupport.org)  
[kidshealth.org/teen/sexual\\_health/girls/pcos.html](http://kidshealth.org/teen/sexual_health/girls/pcos.html)  
[www.nichd.nih.gov/health/topics/Polycystic\\_Ovary\\_Syndrome.cfm](http://www.nichd.nih.gov/health/topics/Polycystic_Ovary_Syndrome.cfm)  
[www.inciid.org/faq.php?cat=infertility101&id=2](http://www.inciid.org/faq.php?cat=infertility101&id=2)

Polycystic Ovarian Syndrome Association  
Coping with Polycystic Ovary Syndrome  
NICHD Patient Information: *Polycystic Ovary Syndrome (PCOS)*  
PCOS Frequently Asked Questions

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[www.hormone.org/polycystic](http://www.hormone.org/polycystic)  
[www.endocrineonline.org/pco3.htm](http://www.endocrineonline.org/pco3.htm)  
[www.endocrineonline.org/pdf%20box/pcos.pdf](http://www.endocrineonline.org/pdf%20box/pcos.pdf)  
[www.soulcysters.com](http://www.soulcysters.com)  
[www.youngwomenshealth.org/pcosinfo.html](http://www.youngwomenshealth.org/pcosinfo.html)  
[www.pofsupport.org](http://www.pofsupport.org)  
[www.endocrineonline.org/pdf%20box/pof.pdf](http://www.endocrineonline.org/pdf%20box/pof.pdf)  
[www.endocrineonline.org/pdf%20box/hrt.pdf](http://www.endocrineonline.org/pdf%20box/hrt.pdf)

The Hormone Foundation: *Polycystic Ovary Syndrome*  
Endocrine Online: *Polycystic Ovarian Syndrome*  
*Polycystic Ovarian Syndrome*  
SoulCysters  
PCOS: *A Guide for Teens*  
Premature Ovarian Failure Support Group  
Endocrine Online: *Premature Ovarian Failure*  
Endocrine Online: *Hormone Replacement Therapy for Young Women*

**Sexuality and sexual differentiation disorders**

[www.bcchildrens.ca/Services/SunnyHillHealthCtr/Learningeducation/EducationResourceCentre/SexualHealth/default.htm](http://www.bcchildrens.ca/Services/SunnyHillHealthCtr/Learningeducation/EducationResourceCentre/SexualHealth/default.htm)

[www.optionsforsexualhealth.org](http://www.optionsforsexualhealth.org)  
[bc.wontgetweird.com](http://bc.wontgetweird.com)  
[www.phac-aspc.gc.ca/publicat/cgshe-ldnemss/index-eng.php](http://www.phac-aspc.gc.ca/publicat/cgshe-ldnemss/index-eng.php)  
[www.phac-aspc.gc.ca/publicat/cgshe-ldnemss/cgshe\\_toc-eng.php](http://www.phac-aspc.gc.ca/publicat/cgshe-ldnemss/cgshe_toc-eng.php)  
[www.phac-aspc.gc.ca/publicat/cgshe-ldnemss/pdf/guidelines-eng.pdf](http://www.phac-aspc.gc.ca/publicat/cgshe-ldnemss/pdf/guidelines-eng.pdf)  
[www.aboutkidshealth.ca/En/HowTheBodyWorks/SexDevelopmentAnOverview/Pages/default.aspx](http://www.aboutkidshealth.ca/En/HowTheBodyWorks/SexDevelopmentAnOverview/Pages/default.aspx)  
[community.pflag.org](http://community.pflag.org)  
[www.pflagcanada.ca](http://www.pflagcanada.ca)  
[community.pflag.org/Page.aspx?pid=380](http://community.pflag.org/Page.aspx?pid=380)  
[www.isna.org](http://www.isna.org)  
[www.accordalliance.org](http://www.accordalliance.org)  
[www.magicfoundation.org](http://www.magicfoundation.org)  
[www.magicfoundation.org/www/docs/107](http://www.magicfoundation.org/www/docs/107)  
[www.magicfoundation.org/www/docs/107.128](http://www.magicfoundation.org/www/docs/107.128)  
[www.magicfoundation.org/www/docs/107.129](http://www.magicfoundation.org/www/docs/107.129)  
[www.magicfoundation.org/www/docs/107.289](http://www.magicfoundation.org/www/docs/107.289)  
[www.magicfoundation.org/www/docs/107.290](http://www.magicfoundation.org/www/docs/107.290)  
[bookstore.cw.bc.ca](http://bookstore.cw.bc.ca)  
[bookstore.cw.bc.ca](http://bookstore.cw.bc.ca)  
[bookstore.cw.bc.ca](http://bookstore.cw.bc.ca)  
[www.dsdguidelines.org/about/consortium](http://www.dsdguidelines.org/about/consortium)  
[www.dsdguidelines.org/files/clinical.pdf](http://www.dsdguidelines.org/files/clinical.pdf)  
[www.dsdguidelines.org/files/parents.pdf](http://www.dsdguidelines.org/files/parents.pdf)  
[www.hopkinschildrens.org/intersex](http://www.hopkinschildrens.org/intersex)  
[www.hopkinschildrens.org/intersex/synd\\_abn\\_sex\\_diff.pdf](http://www.hopkinschildrens.org/intersex/synd_abn_sex_diff.pdf)  
[www.medhelp.org/www/ais](http://www.medhelp.org/www/ais)

Sunny Hill Hospital Sexual Health Resource Centre  
Options for Sexual Health (formerly Planned Parenthood Association of BC)  
BC's Won't Get Weird Sex Information  
Health Canada: Sexual Health Education  
*Canadian Guidelines for Sexual Health Education* (HTML)  
*Canadian Guidelines for Sexual Health Education* (PDF)  
*How the Body Works: Sex Development* (Hospital for Sick Children)  
Parents, Families and Friends of Lesbians and Gays (PFLAG)  
PFLAG Canada  
PFLAG Transgender Network  
Intersex Society of North America  
Accord Alliance  
The MAGIC Foundation  
*Genital and Reproductive Anomalies in Children—General Information*  
*When My Child May Have Fertility Problems*  
*Newborns with Non-Typical Genital Appearance*  
*Hypospadias*  
*Mayer-Rokitansky-Kuster-Hausner Syndrome*  
*It's All Chemistry, for Girls* (to order)  
*It's All Chemistry, for Boys* (to order)  
*This is Slow Growing But Am I Stuck?* (to order)  
Consortium on the Management of Disorders of Sex Differentiation  
*Clinical Guidelines for the Management of Disorders of Sex Differentiation in Children*  
*Handbook for Parents*  
*Syndromes of Abnormal Sex Differentiation: A Guide for Patients and Their Families* (Johns Hopkins)  
Adobe Acrobat® (PDF) format  
Androgen Insensitivity Syndrome Support Group UK

**INTERESTING ENDOCRINE LINKS FOR PATIENTS AND FAMILIES**  
**ENDOCRINOLOGY & DIABETES UNIT HOMEPAGE: <<http://endodiab.bcchildrens.ca>>**

[www.aisdsd.org](http://www.aisdsd.org)  
[home.vicnet.net.au/~aissg](http://home.vicnet.net.au/~aissg)  
[www.rch.org.au/publications/CAIS.html](http://www.rch.org.au/publications/CAIS.html)  
[www.rch.org.au/publications/CAIS.pdf](http://www.rch.org.au/publications/CAIS.pdf)  
[freespace.virgin.net/asg.uk](http://freespace.virgin.net/asg.uk)  
[www.heainfo.org](http://www.heainfo.org)  
[www.urologyhealth.org/urology/pediatrichealth.cfm](http://www.urologyhealth.org/urology/pediatrichealth.cfm)  
[www.xyxo.org](http://www.xyxo.org)  
[www.mrkx.org](http://www.mrkx.org)

**Gender identity / Transgender**

[transhealth.vch.ca](http://transhealth.vch.ca)  
[groups.yahoo.com/group/trans-health](http://groups.yahoo.com/group/trans-health)  
[www.ifge.org](http://www.ifge.org)  
[www.cpath.ca](http://www.cpath.ca)  
[www.wpath.org](http://www.wpath.org)  
[www.wpath.org/Documents2/socv6.pdf](http://www.wpath.org/Documents2/socv6.pdf)  
Public Health Agency of Canada: [www.phac-aspc.gc.ca/publicat/qagis-qrise/pdf/qagis-qrise-eng.pdf](http://www.phac-aspc.gc.ca/publicat/qagis-qrise/pdf/qagis-qrise-eng.pdf)  
[www.gires.org.uk](http://www.gires.org.uk)  
[gires.org.uk/assets/DOH-Assets/pdf/doh-hormone-therapy.pdf](http://gires.org.uk/assets/DOH-Assets/pdf/doh-hormone-therapy.pdf)  
[www.transgendercare.com](http://www.transgendercare.com)  
[www.ctys.org/programs/documents/CTYS\\_FIT\\_Brochure\\_eng.pdf](http://www.ctys.org/programs/documents/CTYS_FIT_Brochure_eng.pdf)  
[www.lambdalegal.org/publications/bending-the-mold/order-bending-the-mold.html](http://www.lambdalegal.org/publications/bending-the-mold/order-bending-the-mold.html)

**Prader–Willi syndrome**

[www.fpwr.ca](http://www.fpwr.ca)  
[www.fpwr.org](http://www.fpwr.org)  
[www.bcpwsa.com](http://www.bcpwsa.com)  
[www.opwsa.com](http://www.opwsa.com)  
[www.pwsnetwork.ca](http://www.pwsnetwork.ca)  
[www.pwsausa.org](http://www.pwsausa.org)  
[www.pwsa.co.uk](http://www.pwsa.co.uk)  
[www.ipwso.org](http://www.ipwso.org)  
[www.ipwso.org/wavelength-newsletters](http://www.ipwso.org/wavelength-newsletters)  
[familyvillage.wisc.edu/lib\\_pws.htm](http://familyvillage.wisc.edu/lib_pws.htm)  
[kc.vanderbilt.edu/site/topics/155/prader-willi-syndrome.aspx](http://kc.vanderbilt.edu/site/topics/155/prader-willi-syndrome.aspx)  
[www.pwsnotes.org](http://www.pwsnotes.org)

AIS–DSD Support Group for Women and Families  
Androgen Insensitivity Syndrome Support Group Australia  
*Complete Androgen Insensitivity Syndrome* (Dr. Gary Warne)  
Adobe Acrobat® (PDF) format  
Anorchidism Support Group (UK)  
Hypospadias & Epispadias Association  
UrologyHealth: Pediatric Conditions  
Mixed Gonadal Dysgenesis Support Group  
MRKH.org (Mayer–Rokitansky–Kuster–Hauser Syndrome)

Vancouver Coastal Health Transgender Health Program  
trans-health: Transgender Health Program list server (British Columbia)  
International Foundation for Gender Education  
Canadian Professional Association for Transgender Health  
World Professional Association for Transgender Health, Inc.  
*Standards of Care for Gender Identity Disorders (6th version)*  
*Questions & Answers: Gender Identity in Schools*  
Gender Identity Research and Education Society (GIRES)  
*A Guide to Hormone Therapy for Trans People*  
TransGenderCare  
*Families in TRANSition: A Resource Guide for Parents of Trans Youth*  
Lambda Legal: *Bending the Mold: An Action Kit for Transgender Students*

Foundation for Prader–Willi Research Canada  
Foundation for Prader–Willi Research USA  
British Columbia Prader–Willi Syndrome Association  
Ontario Prader–Willi Syndrome Association  
Prader–Willi Syndrome Network  
Prader–Willi Syndrome Association (USA)  
Prader–Willi Syndrome Association (UK)  
International Prader–Willi Syndrome Organisation  
*Wavelength*  
*The Family Village* entry on PWS  
Vanderbilt Kennedy Center PWS Research  
PWS Notes

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**Turner syndrome**

[www.turnersyndrome.org](http://www.turnersyndrome.org)  
[www.turnersyndrome.org/dmdocuments/TSfamily\\_guide092502B.pdf](http://www.turnersyndrome.org/dmdocuments/TSfamily_guide092502B.pdf)  
[www.tsregistry.org](http://www.tsregistry.org)  
[www.bctsnetwork.org](http://www.bctsnetwork.org)  
[www.turnersyndrome.ca](http://www.turnersyndrome.ca)  
[www.syndrometurnerquebec.com](http://www.syndrometurnerquebec.com)  
[www.tss.org.uk](http://www.tss.org.uk)  
[turners.nichd.nih.gov](http://turners.nichd.nih.gov)  
[www.magicfoundation.org/www/docs/115](http://www.magicfoundation.org/www/docs/115)  
[www.hormone.org/Resources/Growth/loader.cfm?csModule=security/getfile&pageid=1106](http://www.hormone.org/Resources/Growth/loader.cfm?csModule=security/getfile&pageid=1106)  
[www.hgfound.org/pub\\_turner.html](http://www.hgfound.org/pub_turner.html)  
[www.endocrineonline.org/ts2.htm](http://www.endocrineonline.org/ts2.htm)  
[www.endocrineonline.org/pdf%20box/ts%20health.pdf](http://www.endocrineonline.org/pdf%20box/ts%20health.pdf)

Turner Syndrome Society of the US  
*Turner Syndrome: A Guide for Families*  
Turner Society International Registry  
BC Turner Society Network  
Turner's Syndrome Society of Canada  
L'association du Syndrome de Turner du Québec  
UK Turner Syndrome Support Society  
Clinical Studies of Turner Syndrome at NICHD  
The MAGIC Foundation: *Turner Syndrome—General Information*  
The Hormone Foundation: *Turner Syndrome*  
Human Growth Foundation: *Turner Syndrome*  
Endocrine Online: *Turner Syndrome in Adults*  
*Health Care Issues for Women with Turner Syndrome*

**Williams syndrome**

[www.williams-syndrome.org](http://www.williams-syndrome.org)  
[www.wsf.org](http://www.wsf.org)  
[www.williams-syndrome.org.uk](http://www.williams-syndrome.org.uk)

Williams Syndrome Association  
Williams Syndrome Foundation  
Williams Syndrome Foundation (UK)

**DiGeorge syndrome / Velocardiofacial syndrome**

[www.vcfsef.org](http://www.vcfsef.org)  
[www.familyvillage.wisc.edu/lib\\_dig.htm](http://www.familyvillage.wisc.edu/lib_dig.htm)  
[www.chop.edu/service/22q-and-you-center/home.html](http://www.chop.edu/service/22q-and-you-center/home.html)  
[www.nt.net/~a815](http://www.nt.net/~a815)  
[www.22q.org](http://www.22q.org)

Velo-Cardio-Facial Syndrome (VCFS) Educational Foundation  
Family Village Factsheet: *DiGeorge Syndrome*  
22q and You Center  
Chromosome 22 Central  
International 22q11.2 Deletion Syndrome Foundation, Inc

**Russell–Silver syndrome**

[www.magicfoundation.org/www/docs/112](http://www.magicfoundation.org/www/docs/112)  
[www.familyvillage.wisc.edu/lib\\_rss.htm](http://www.familyvillage.wisc.edu/lib_rss.htm)  
[www.russell-silversupport.org](http://www.russell-silversupport.org)

The MAGIC Foundation: *Russell–Silver Syndrome—General Information*  
Family Village Factsheet: *Russell–Silver Syndrome*  
Russell–Silver Syndrome Support

**Noonan syndrome**

[www.noonansyndrome.org](http://www.noonansyndrome.org)

Noonan Syndrome Support Group

**McCune–Albright syndrome**

[www.magicfoundation.org/www/docs/109](http://www.magicfoundation.org/www/docs/109)  
[www.paget.org/index.php/patients/fibrous-dysplasia.html](http://www.paget.org/index.php/patients/fibrous-dysplasia.html)

The MAGIC Foundation: *McCune–Albright Syndrome—General Information*  
The Paget Foundation: *Fibrous Dysplasia*

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[www.nichd.nih.gov/health/topics/McCune\\_Albright\\_Syndrome.cfm](http://www.nichd.nih.gov/health/topics/McCune_Albright_Syndrome.cfm)  
[fdsol.org](http://fdsol.org)

NICHD Patient Information: *McCune-Albright Syndrome*  
Fibrous Dysplasia Support Online

**Klinefelter syndrome**

[www.genetic.org](http://www.genetic.org)  
[klinefeltersyndrome.org](http://klinefeltersyndrome.org)  
[www.aaksis.org](http://www.aaksis.org)  
[www.ksa-uk.co.uk](http://www.ksa-uk.co.uk)  
[intramural.nimh.nih.gov/chp/xyy](http://intramural.nimh.nih.gov/chp/xyy)  
[www.nichd.nih.gov/health/topics/klinefelter\\_syndrome.cfm](http://www.nichd.nih.gov/health/topics/klinefelter_syndrome.cfm)  
[47xxy.org](http://47xxy.org)

KS&A: Knowledge, Support & Action  
Klinefelter Syndrome Support Group  
American Association for Klinefelter Syndrome Information and Support  
Klinefelter's Syndrome Association UK  
NIMH: Klinefelter Syndrome (KS) and Other Sex Chromosome Variations  
NICHD Patient Information: *Klinefelter Syndrome*  
47,XXY Klinefelter Syndrome

**Marfan syndrome**

[www.marfan.ca](http://www.marfan.ca)  
[www.marfan.org](http://www.marfan.org)

Canadian Marfan Foundation  
National Marfan Foundation

**Metabolic bone disease / osteoporosis**

[www.xlhnetwork.org](http://www.xlhnetwork.org)  
[www.osteoporosis.ca](http://www.osteoporosis.ca)  
[www.niams.nih.gov/Health\\_Info/Bone](http://www.niams.nih.gov/Health_Info/Bone)  
[www.niams.nih.gov/Health\\_Info/Bone/Osteogenesis\\_Imperfecta/default.asp](http://www.niams.nih.gov/Health_Info/Bone/Osteogenesis_Imperfecta/default.asp)  
[www.niams.nih.gov/Health\\_Info/Bone/Bone\\_Health/Juvenile/default.asp?print=yes](http://www.niams.nih.gov/Health_Info/Bone/Bone_Health/Juvenile/default.asp?print=yes)  
[www.nof.org](http://www.nof.org)  
[www.oif.org](http://www.oif.org)  
[www.oif.org/site/DocServer?docID=803](http://www.oif.org/site/DocServer?docID=803)  
[health.groups.yahoo.com/group/OIparents](http://health.groups.yahoo.com/group/OIparents)  
[www.oife.org](http://www.oife.org)  
[www.cbbf.org](http://www.cbbf.org)

X-Linked Hypophosphatemic Rickets Network  
Osteoporosis Society of Canada  
NIAMS/NIH Osteoporosis and Related Bone Diseases National Resource Center  
*Osteogenesis Imperfecta*  
*Kids and Their Bones: A Guide for Parents*  
National Osteoporosis Foundation  
Osteogenesis Imperfecta Foundation  
*Update on Bisphosphonates as a Treatment for Osteogenesis Imperfecta*  
OIparents (Yahoo Group)  
Osteogenesis Imperfecta Federation Europe  
Children's Brittle Bone Foundation

**Hyperinsulinism / Hypoglycemia**

[www.chop.edu/service/congenital-hyperinsulinism-center/home.html?id=47690](http://www.chop.edu/service/congenital-hyperinsulinism-center/home.html?id=47690)  
[www.hi-fund.org](http://www.hi-fund.org)  
[www.sur1.org](http://www.sur1.org)  
[www.congenitalhi.org](http://www.congenitalhi.org)  
[health.groups.yahoo.com/group/hyperins](http://health.groups.yahoo.com/group/hyperins)

Congenital Hyperinsulinism Center (CHOP)  
Children's Hyperinsulinism Fund (UK)  
sur1.org: The Website for Families of Children with Hyperinsulinism  
Congenital Hyperinsulinism International  
Yahoo PHHI Discussion Group

**Genetics resources**

[www.lhsc.on.ca/Patients\\_Families\\_Visitors/Genetic\\_Support\\_Directory](http://www.lhsc.on.ca/Patients_Families_Visitors/Genetic_Support_Directory)

Canadian Directory of Genetic Support Groups

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[www.geneticalliance.org](http://www.geneticalliance.org)  
[www.ncbi.nlm.nih.gov/sites/entrez?db=omim](http://www.ncbi.nlm.nih.gov/sites/entrez?db=omim)  
[www.genome.gov/glossary.cfm?](http://www.genome.gov/glossary.cfm)

The Alliance of Genetic Support Groups  
Online Mendelian Inheritance in Man  
Talking Glossary of Genetic Terms

**Rare diseases and support groups**

[endocrine.niddk.nih.gov/resources/organizations.aspx](http://endocrine.niddk.nih.gov/resources/organizations.aspx)  
[www.raredisorders.ca](http://www.raredisorders.ca)  
[www.rarediseasefoundation.org](http://www.rarediseasefoundation.org)  
[www.rarediseases.org](http://www.rarediseases.org)  
[rarediseases.info.nih.gov](http://rarediseases.info.nih.gov)  
[www.magicfoundation.org/www/docs/111](http://www.magicfoundation.org/www/docs/111)  
[ghr.nlm.nih.gov/ghr](http://ghr.nlm.nih.gov/ghr)  
[www.nichcy.org](http://www.nichcy.org)  
[www.birthdefects.org](http://www.birthdefects.org)  
[www.familysupportbc.com](http://www.familysupportbc.com)  
[www.hc-sc.gc.ca](http://www.hc-sc.gc.ca)  
[www.phac-aspc.gc.ca/hp-ps/dca-dea/index-eng.php](http://www.phac-aspc.gc.ca/hp-ps/dca-dea/index-eng.php)  
[www.familyvillage.wisc.edu/specific.htm](http://www.familyvillage.wisc.edu/specific.htm)  
[www.orpha.net](http://www.orpha.net)  
[www.eparent.com](http://www.eparent.com)  
[www.microboard.org](http://www.microboard.org)  
[www.medicalert.ca](http://www.medicalert.ca)  
[www.medicalert.ca/en/why/assistance.pdf](http://www.medicalert.ca/en/why/assistance.pdf)

NIDDK Directory of Endocrine and Metabolic Diseases Organizations  
Canadian Organization for Rare Disorders (CORD)  
Rare Disease Foundation  
The National Organization of Rare Disorders  
NIH Office of Rare Diseases  
The MAGIC Foundation: *Rare Disorders*  
Genetics Home Reference  
The National Information Center for Children and Youth with Disabilities  
Birth Defect Research for Children  
Family Support Institute (BC)  
Health Canada Online  
Childhood & Adolescence  
Family Village Specific Diagnoses Card Catalog  
ORPHA.NET  
Exceptional Parent / PediaNet  
Vela Microboard Association of BC  
MedicAlert Canada  
Membership Assistance Application

**Other disorders**

[endocrine.niddk.nih.gov/pubs/men1/men1.aspx](http://endocrine.niddk.nih.gov/pubs/men1/men1.aspx)  
[www.cc.nih.gov/ccc/patient\\_education/pepubs/pheo.pdf](http://www.cc.nih.gov/ccc/patient_education/pepubs/pheo.pdf)  
[www.amend.org.uk](http://www.amend.org.uk)  
[www.ctf.org](http://www.ctf.org)  
[beckwith-wiedemann.org](http://beckwith-wiedemann.org)  
[www.sssac.com](http://www.sssac.com)  
[www.sotosyndrome.org](http://www.sotosyndrome.org)  
[www.vhl.org](http://www.vhl.org)  
[www.aarda.org](http://www.aarda.org)  
[www.survivorshipguidelines.org](http://www.survivorshipguidelines.org)  
[www.cancersurvivorlink.org](http://www.cancersurvivorlink.org)

NIDDK Patient Information: *Multiple Endocrine Neoplasia Type 1*  
NIH Patient Information: *Pheochromocytoma*  
Association for Multiple Endocrine Neoplasia Disorders (AMEND)  
Children's Tumor Foundation: Ending Neurofibromatosis Through Research  
Beckwith–Wiedemann Support Network  
Sotos Syndrome Support Association Canada  
Sotos Syndrome Support Association USA  
von Hippel-Lindau Family Alliance  
American Autoimmune Related Diseases Association  
*Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers*  
Cancer SurvivorLink