www.eurordis.org



How to optimize your Internet search for rare disease information with Google

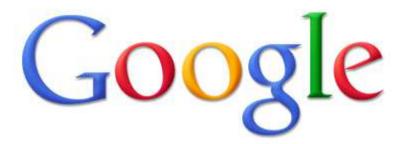
EURORDIS Online Training

David OZIEL EURORDIS



Part 1

Google, the most popular search engine



.

Advanced search Language tools

Google Search

I'm Feeling Lucky

Your name is Galloping Gertie. How many furlongs long are you?

Advertising Programs

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Search engines: how they work

- Computer programs (robots, crawlers, spiders)
- Searching the web
- Following links from page to page
- Collecting full text information
- Storing the information in a database





cystinosis



Search

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Learn

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See you

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Something different cystic fibrosis adpkd cystinuria galactosemia hemochromatosis

Cystinosis - Wikipedia, the free encyclopedia

Cystinosis is a lysosomal storage disease characterized by the abnormal accumulation of the amino acid cystine. It is a genetic disorder that typically ...

Diagnosis - Genetics - Treatment - Types en.wikipedia.org/wiki/Cystinosis - Cached - Similar

Cystinosis Q

31 Aug 2009 ... Nephropathic **cystinosis** is an inherited (autosomal recessive) lysosomal storage disorder caused by defective transport of the amino acid ... emedicine.medscape.com/article/981650-overview - Cached - Similar

Cystinosis - Genetics Home Reference Q

Cystinosis is a condition in which the body accumulates the amino acid cystine (a building block of proteins) within cells. Excess cystine forms crystals ... ghr.nlm.nih.gov/condition/cystinosis - Cached - Similar

Cystinosis Research Network (CRN) - Vision is the discovery of ... Q

The Cystinosis Research Network is a volunteer, non-profit organization dedicated to supporting and advocating research, providing family assistance and ... www.cystinosis.org/ - Cached - Similar

BBC - Health: Cystinosis Q

BBC **Cystinosis** A guide to the causes, symptoms and treatment of **Cystinosis**. www.bbc.co.uk/health/.../**cystinosis**1.shtml - Cached - Similar - Add to iGoogle

Cystinosis Research Foundation - About Cystinosis Q

Cystinosis is a rare, **cystinosis** affects 500 people mostly children, in the United States. **Cystinosis** is a genetic metabolic disease that causes cystine, ...

Cystinosis Foundation An Example

The **Cystinosis** Foundation is a non-profit, with more than 25 years of International expens in supporting and ed **Cystinosis — Atrare disease**

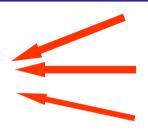


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Cystinosis Foundation - 25 Years of International Experience Q

The ORIGINAL **Cystinosis** Foundation. We are a non-profit organization, with more than 25 years of International experience in supporting and educating ... www.cystinosisfoundation.org/ - Cached - Similar



Part 2 Basic tips for Google search





Part 2: Five tips for Google Search

- Tip #1: Writing search terms
- Tip #2: Search with two or more terms
- Tip #3: Search with quoted phrases
- Tip #4: Search with the OR operator
- Tip #5: Exclude terms from a search







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Something different

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glycine leucine cystine

cystine

cystinosis

cystin**uria**

cystine kidney stones

cystine stones

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Cystine - Wikipedia, the free encyclopedia 3

Cystine is a dimeric amino acid formed by the oxidation of two cysteine residues that covalently link to make a disulfide bond. ... en.wikipedia.org/wiki/**Cystine** - Cached - Similar

Cystine amino acid information page. All about cystine and the ...

24 Jan 2011 – **Cystine**, as an amino acids, forms part of your daily diet, and plays a certain role in maintaining your health, vitality and wellbeing.

www.anyvitamins.com/cystine-info.htm - Cached - Similar

Cystinuria (Cystine in the Urine / Cystine Stones) Causes ...

27 Jun 2011 – Learn about Cystinuria - an excess of **cystine / cystine** stones in the urine. Includes causes, symptoms, signs, and treatment.

www.medicinenet.com > ... > cystinuria index - Cached - Similar

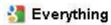
Treatment of Cystine Stones 3 9

Since to stop **cystine** calculi in most patients it is sufficient to dilute urinary **cystine** concentration down to 300 mg/liter, for a patient with a daily ... www.cystinuria.com/articles/treatment-of-cystine-stones/ - Cached - Similar

Tip #1 Writing Search Terms

















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Cystinosis is a condition in which the body accumulates the amino acid cystine (a building block of proteins) within cells. Excess cystine forms crystals ... ghr.nlm.nih.gov/condition/**cystinosis** - Cached - Similar.

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Part 2: Five tips for Google Search

Tip #1: Writing search terms

Tip #2: Search with two or more terms

Tip #3: Search with quoted phrases

Tip #4: Search with the OR operator

Tip #5: Exclude terms from a search



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Thalassemia Treatment | Cure2Children.org Q

www.cure2children.org/Thalassemia

Read FAQ to be Thalassemia-free with Bone Marrow Transplantation

Thalassemia treatment Q

www.nhlbi.nih.gov/.../Thalassemia/Thalassemia_Treatments.html

Treatments for thalassemias depend on the type and severity of the disorder.

Thalassemia - Symptoms, Diagnosis, Treatment of Thalassemia - NY ... 🔍

health.nytimes.com > Times Health Guide > t

31 Jan 2010 ... **Treatment** for **thalassemia** major often involves regular blood transfusions and folate supplements. If you receive blood transfusions, ...

Alpha and Beta Thalassemia Causes, Symptoms, Treatment and ... Q

www.medicinenet.com > home > alpha thalassemia index

15 Jun 2011 ... Blood tests and family genetic studies can show whether an individual has **thalassemia** or is a carrier. If both parents are carriers, ...

All results

alassemia TreatmerTip #2

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- Tip #1: Writing search terms
- Tip #2: Search with two or more terms
- Tip #3: Search with quoted phrases
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- Tip #5: Exclude terms from a search





"thalassemia treatment" × Search

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Thalassemia Treatment | Cure2Children.org

www.cure2children.org/Thalassemia

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Thalassemia treatment Q

www.nhlbi.nih.gov/health/dci/.../Thalassemia_Treatments.html

Treatments for thalassemias depend on the type and severity of the disorder.

Thalassemia Treatment, Center For Prenatal Diagnosis, Thalassemia ...

www.thalassemicsindia.org/treatment.html

Thalassemics India - thalassemia treatment, center for prenatal diagnosis, thalassemia treatment center, prenatal diagnosis india, ...

Pediatric Thalassemia Treatment & Management Q

emedicine.medscape.com/article/958850-treatment

30 Apr 2010 ... Treatment & Management: Pediatric Thalassemia. The thalassemias are inherited disorders of hemoglobin (Hb) synthesis.

Thalasaemia. **Thalassemia Treatment** Thalasaemia Altorrativa.....

Thalassemia Treatment of Chine is 10 1,43 ternative Neuro Acupuncture Treatment an Thalassemia Herbal Herbs Remedies Medicine Treatment on Acupuncture ...

Search with quoted phrases

www.webmd.com/a-to-z.../thalassemia-treatment-overview



S

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- Tip #1: Writing search terms
- Tip #2: Search with two or more terms
- Tip #3: Search with quoted phrases
- Tip #4: Search with the OR operator
- Tip #5: Exclude terms from a search





thalassemia treatment OR diagnosis



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Thalassemia treatment Q

www.nhlbi.nih.gov/.../Thalassemia/Thalassemia_Treatments.htm//
Treatments for thalassemias depend on the type and severity of the disorder.

Diagnosis of thalassemias Q

www.nhlbi.nih.gov/.../Thalassemia/Thalassemia Diagnosis/htm/

Doctors diagnose thalassemias using blood tests, including a complete blood ...

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Thalassemia - Symptoms, Diagnosis, Treatment of Thalassemia - NY ... 🔍

health.nytimes.com > Times Health Guide > t

31 Jan 2010 ... Treatment for thalassemia major often involves regular blood transfusions and folate supplements. If you receive blood transfusions, ...

Alpha and Beta Thalassemia Causes, Symptoms, Treatment and ... Q

www.medicinenet.com > home > alpha thalassemia index

15 Jun 2011 ... Alpha thalassemia is a blood disorder that reduces the production

Treatment for sickle cell anemia aims to manage and prevent the worst ...

[PDF] INTRODUCTION DIAGNOSIS OF THALASSEMIA

www.thalassemia.com/Thal SOC guide.pdf

File Format: PDF/Adobe Acrobat - Quick View

9 Jun 2000 ... DIAGNOSIS OF THALASSEMIA. Prior to consideration of transfusion therapy,

s critical in confirm that the #Tip #4

Search with the OR operator





"mucopolysaccharidosis type III"

× Sea

"mucopolysaccharidosis type 3"

Search

About 38,800 results (0.21 seconds)

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Advanced search

Scholarly articles for "mucopolysaccharidosis type III"



A mouse model for mucopolysaccharidosis type III A (... - Bhaumik - Cited by 65 Management of mucopolysaccharidosis type III. - Cleary - Cited by 55 ... follow-up in mucopolysaccharidosis type III (Sanfilippo ... - Barone - Cited by 27

Genetics of Mucopolysaccharidosis Type III Q

14 May 2009 ... The mucopolysaccharidoses (MPSs) are a rare group of inherited lysosomal storage disorders that are caused by the deficiency or absence of ... emedicine.medscape.com/article/948540-overview - Cached - Similar

Genetics of Mucopolysaccharidosis Type III Treatment & Management Q

14 May 2009 ... Treatment & Management:Genetics of Mucopolysaccharidosis ... emedicine.medscape.com/article/948540-treatment - Cached - Similar

■ Show more results from medscape.com

Mucopolysaccharidosis type III - Genetics Home Reference Q

Mucopolysaccharidosis type III (MPS III), also known as Sanfilippo syndrome, is a progressive disorder that mainly affects the brain and spinal cord ...

gbr nlm.nib.gov/condition/mucopolysaccharidosis-type-iii - Cached - Similar



"mucopolysaccharidosis 3"

About 640 results (0.15 seconds)

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► Orphanet: Mucopolysaccharidosis type 3

Mucopolysaccharidosis type 3. Orpha number, ORPHA581. Prevalence of rare diseases, 1-9 / 100 000. Inheritance. Autosomal recessive. Age of onset, Childhood ... www.orpha.net/consor/cgi-bin/OC Exp.php?Ing=EN... - Cached - Similar

Mucopolysaccharidosis type 3 - definition of Mucopolysaccharidosis ... Q

Noun, 1. mucopolysaccharidosis - any of a group of genetic disorders involving a defect in the metabolism of mucopolysaccharides resulting in greater than ...

www.thefreedictionary.com/Mucopolysaccharidosis+type+3 - Cached

Mucopolysaccharidosis type 3 - definition of Mucopolysaccharidosis ... Q

mucopolysaccharidosis /mu·co·pol·y·sac·cha·ri·do·sis/ (-sak"ah-ri-do´sis ...
medical-dictionary.thefreedictionary.com/Mucopolysaccharidosis+type+3 - Cached



"sanījiippo syndrome"

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Mucopolysaccharidosis 3 Definition in Medical Conditions Dictionary Q.

Definition of the term **Mucopolysaccharidosis** 3: Mucopolysaccharidosis characterized by heparitin sulfate in the urine, progressive mental retardation, ... medconditions.net/mucopolysaccharidosis-3.html - Cached

Sanfilippo syndrome (mucopolysaccharidosis 3).

by J Abraham - 1970 - Cited by 3 - Related articles

Sanfilippo syndrome (mucopolysaccharidosis 3). Abraham J, Shetty G, Bhakthaviziam A, Chakrapani B, Kokrady S, Bachhawat BK. PMID: 4250212 [PubMed - indexed ... www.ncbi.nlm.nih.gov/pubmed/4250212

Sanfilippo syndrome: MedlinePlus Medical Encyclopedia Q

Sanfilippo syndrome is an inherited disease of metabolism that makes the body unable to properly break down long chains of sugar molecules called ...

www.nlm.nih.gov/medlineplus/encv/article/001210.htm - Cached - Similar

Sanfilippo syndrome - Wikipedia, the free encyclopedia Q

Sanfilippo syndrome, or Mucopolysaccharidosis III (MPS-III) is a rare autosomal recessive lysosomal storage disease caused by a deficiency in one of the ... Incidence - Pathophysiology - Diagnosis and Natural History - Treatment

Mucopolysaccharidosis 3. A. (Canfilippo. A. disease) ...deficience esta a uni

by H Kresse 1997 1 Oct 1973 1999 www.ncbi.nl

Mucopolysaecharidosis 3: A (Santhopo A diseasa), dehoiead

Tip#4

es Sanfilippes Syndiome

Search with the OR operator





"mucopolysaccharidosis type III" OR "mucopolysaccharidosis type 3" OF



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Scholarly articles for "mucopolysaccharidosis type III" OR "mucopolysaccharidosis type 3" OR "mucopolysaccharidosis 3" OR "sanfilippo syndrome"



Sanfilippo syndrome: profound deficiency of alpha- ... - O'brien - Cited by 97 Mouse model of Sanfilippo syndrome type B produced ... - Li - Cited by 86 ... variability in the Sanfilippo syndrome (types A, B, and ... - Kamp - Cited by 78

Sanfilippo syndrome: MedlinePlus Medical Encyclopedia 🔍

Sanfilippo syndrome is an inherited disease of metabolism that makes the body unable to properly break down long chains of sugar molecules called ... www.nlm.nih.gov/medlineplus/ency/article/001210.htm - Cached - Similar

Mucopolysaccharidosis type III - Genetics Home Reference Q

Mucopolysaccharidosis type III (MPS III), also known as Sanfilippo syndrome ... ghr.nlm.nih.gov/condition/mucopolysaccharidosis-type-iii - Cached - Similar

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Orphanet: Mucopolysaccharidosis type 3 Q

Mucopolysaccharidosis type III (MPS III) is a lysosomal storage disease belonging to the group of mucopolysaccharidoses and characterised by severe and ... www.orpha.net/consor/cgi-bin/OC Exp.php?Ing=EN... - Cached - Similar

Mucopolysaccharidosis 3 Definition in Medical Conditions Dictionary Q

Definition of the term Mucopolysaccharidosis 3: Mucopolysaccharidosis characterized by heparitin sulfate in the urine, progressive mental retardation, ... medconditions.net/mucopolysaccharidosis-3.html - Cached

an A. **Search with the OR operator**



Part 2 Basic Tips for Google Search

- Tip #1: Writing search terms
- Tip #2: Search with two or more terms
- Tip #3: Search with quoted phrases
- Tip #4: Search with the OR operator
- Tip #5: Exclude terms from a search





"health inequalities" -"social determinants"



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HO: Health Inequalities

Health Inequalities. ... Return to Listing. Health Inequalities. Health Inequalities Overview

· Basket of Indicators · Marmot Indicators ...

www.lho.org.uk/LHO_Topics/.../HealthInequalities.aspx - Cached - Similar

Tackling health inequalities: A Programme for Action: Department ... Q

2 Jul 2003 ... This Programme for Action sets out plans to tackle health inequalities over the next three years.

www.dh.gov.uk > Home > Publications - Cached - Similar

Health Inequalities: UK National Statistics Publication Hub Q

Trends in Health Inequalities between both the 20% most deprived areas and rural areas within Trust areas compared with Trusts as a whole are reported ...

www.statistics.gov.uk/hub/health-social-care/.../health-inequalities - Similar.

VicHealth - Health Inequalities Q

Why address inequalities in health? There are marked inequalities in health between different groups of people in Victoria, including differences in rates ...

www.vichealth.vic.gov.au/Programs.../Health-Inequalities.aspx - Cached - Similar

BBC News - Poorest in England 'live seven years less on average'

11 Feb 2010 ... Warning over health inequalities 14 Oct 08 | Health, Call for health

inequalities push 24 Jun 08 | Health, Health inequality gap 'widening' bha an ul Mihithaalth/9509204 atm. Cool

Tip#5

Tip #5: Exclude terms from a search

Part 3

Tips for a more effective search





- Tip #1: Carefully select search terms
- Tip #2: Limit the number of search terms
- Tip #3: Think of word variations and synonyms
- Tip #4: Identify alternative terms
- Tip #5: Pay attention to the URL's
- Tip #6: Filter your search
- Tip #7: Discover the new features from Google



 What are the effects of growth hormone therapy on children with Prader-Willi syndrome?

 What are the effects of growth hormone therapy on children with Prader-Willi syndrome?

effects growth hormone therapy
 children Prader-Willi syndrome ?

growth hormone children Prader-Willi





growth hormone children prader willi

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Scholarly articles for growth hormone children prader willi



<u>Growth hormone treatment of children with Prader-Willi</u> - Lindgren - Cited by 108 ... <u>hormone secretion and effects of growth hormone</u> - Angulo - Cited by 96 ... physical strength and agility, and growth in Prader-Willi ... - Myers - Cited by 86

Growth Hormone and Prader-Willi syndrome

Efficacy And Safety Of Long-Term Continuous Growth Hormone Treatment In Children With Prader-Willi Syndrome [Click here]; Growth Hormone Consensus Statement ...

www.pwsausa.org/GH/ - Cached - Similar

PWSA(USA) Policy Statement: Growth Hormone Treatment and Prader ... 🕡 🔍

Angulo, M., et al: Growth hormone secretion and effects of growth hormone ... www.pwsausa.org/postion/ps001.htm - Cached - Similar

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Five years of growth hormone treatment in children with Prader

by AC Lindgren - 1999 - Cited by 59 - Related articles

The authors have followed 18 prepubertal children (3-12 years of age) with Prader-Willi syndrome during 5 years of growth hormone (GH) treatment. ... www.ncbi.nlm.nih.gov/pubmed/10626558

Medical News: LWPES: Early Growth Hormone Therapy Changes Prader ... 🕣 🔍

4 May 2010 ... By treating these **children** with recombinant human **growth hormone** (hGH) ... of 48 **children** with **Prader-Willi** syndrome at the meeting of the ... www.medpagetoday.com > Meeting Coverage > LWPES - Cached - Similar

Prader-Willi Syndrome (PWS): Your Child: University of Michigan ... 🖅 🔍

Prader-Willi syndrome (PWS) is a genetic syndrome that affects one in every ... Get the Facts: Growth Hormone Issues in Children and Adults is a 16-page ... www.med.umich.edu/1libr/yourchild/praders.htm - Cached - Similar

Prader-Willi syndrome - Wikipedia, the free encyclopedia 🖅 🔍

"Effect of growth hormone on height, weight, and body composition in Prader-Willi syndrome". Arch. Dis. Child. 78 (5): 474–6, doi:10.1136/adc.78.5.474. ... en.wikipedia.org/wiki/Prader-Willi syndrome - Cached - Similar

Growth Hormone Therapy » Prader-Willi Syndrome Association New Zealand 💷 🔍

In **children** with **Prader-Willi** Syndrome funding for **growth hormone** will be available where: a diagnosis of PWS has been confirmed by genetic testing; and ... www.pws.org.nz/**growth-hormone**-therapy/ - Cached

[PDF]

EFFECTS OF GROWTH HORMONE TREATMENT IN CHILDREN WITH PRADER-WILLI



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- Tip #3: Think of word variations and synonyms
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 What are the side effects of treatments for multiple sclerosis?

 What are the side effects of treatments for multiple sclerosis?

- side effects treatments multiple sclerosis
- multiple sclerosis



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Kidney cysts

Cyst, cysts, cystic

Renal cysts

cyst OR cysts OR cystic kidney OR renal

 Kidney cyst, kidney cysts, renal cyst, cystic kidney,...





cyst OR cysts OR cystic kidney OR renal

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Kidney Cysts -- familydoctor.org 🖅 🔍

Kidney cysts are sacs filled with fluid that form in the kidneys. Learn about the causes, diagnosis and treatment of **kidney cysts**.

familydoctor.org > familydoctor.org Home > Conditions AZ - Cached - Similar

Simple Kidney Cysts

Cysts that form on the kidneys usually contain fluid. One or more cysts may develop on small tubes in the kidneys. The simple **kidney** cyst is different from ... **kidney**.niddk.nih.gov/kudiseases/pubs/cysts/ - Cached - Similar

Cystic Diseases of the Kidney

15 Dec 2010 ... One third of people older than 50 years develop **renal cysts**. emedicine.medscape.com/article/453831-overview - Cached - Similar

Kidney cysts - MayoClinic.com 💷 🔍

Kidney cysts — Overview covers symptoms, complications and treatment of simple **kidney cysts**.

www.mayoclinic.com/health/kidney-cysts/DS01186 - Cached - Similar

There are two significant categories of **kidney cysts** that exist. The most common type of **kidney cyst** is the simple **kidney cyst** and the other is called the ... www.**kidney**cancerinstitute.com/**kidney-cyst**.html - Cached - Similar

Cystic Kidney Disease 1 9

29 Dec 2010 ... Polycystic **kidney** disease (PKD) is a genetic disorder characterized by the growth of numerous **cysts** in the kidneys. The **cysts** are filled ... www.mcw.edu > mcw.edu > Nephrology > Clinical Services - Cached - Similar

Could my kidney cysts be cancerous? - CNN.com 💷 🔍

6 Jan 2010 ... I have a **cyst** in each of my kidneys. Can this be cancerous? www.cnn.com/2010/HEALTH/.../kidney.cysts.../index.html - Cached - Similar

Are kidney cysts normal? - UK National Kidney Federation 🖅 🔍

27 Feb 2011 \dots A **cyst** is a swelling. In the **kidney**, **cysts** are round, have a very thin, clear wall and are usually filled with watery fluid. \dots

www.kidney.org.uk/Medical-Info/kidney-disease/cysts.html - Cached - Similar

A **renal cyst** is a fluid collection in the **kidney**. There are several types based on the Bosniak classification. The majority are benign, simple **cysts** that ... en.wikipedia.org/wiki/**Renal_cyst** - Cached - Similar

Renal Cystic Disease 💷 🔍

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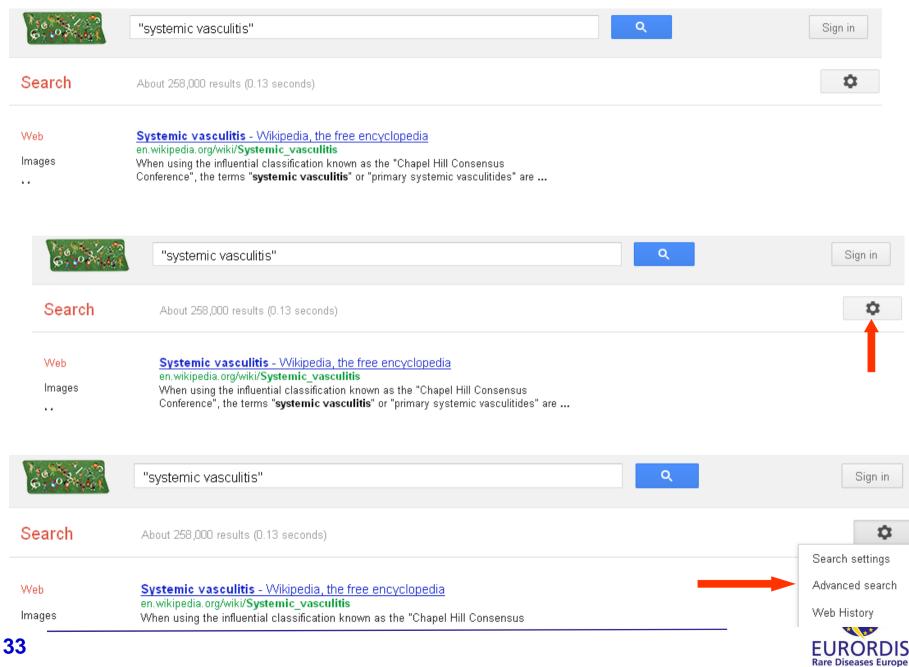


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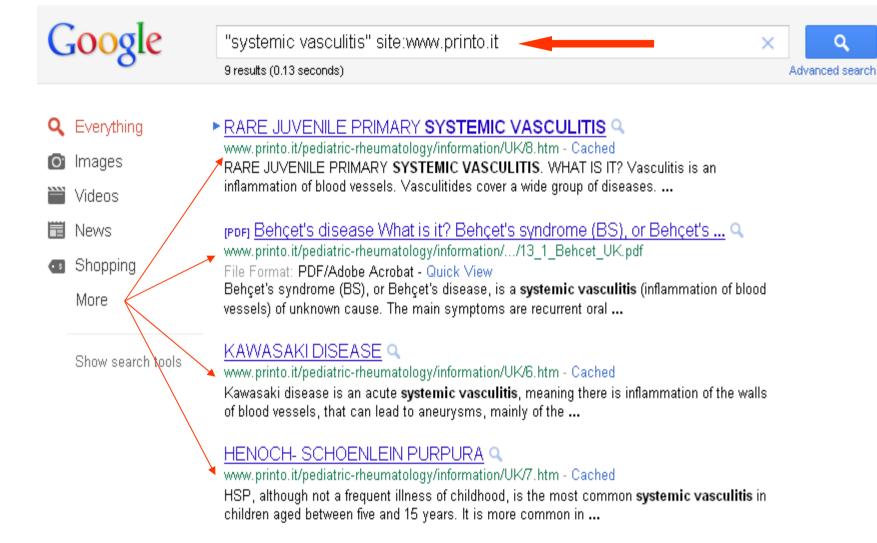




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	(e.g. youtube.com, .edu)							
■ Date, usage rights, region, and more								
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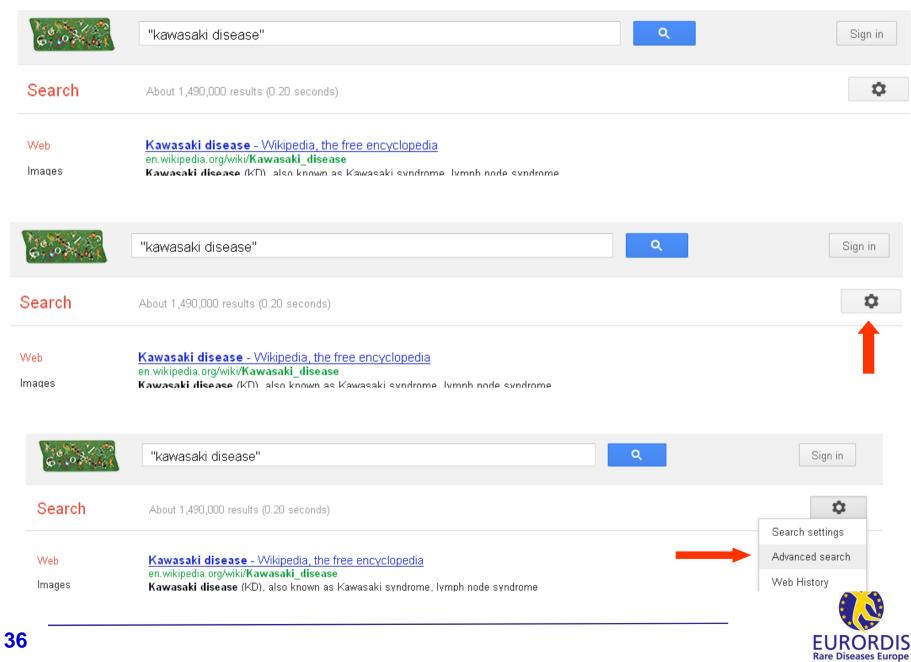
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Kawasaki Disease: MedlinePlus Q

www.nlm.nih.gov/medlineplus/kawasakidisease.html

6 May 2011 ... Kawasaki disease is a rare childhood disease. It makes the walls of the blood vessels throughout the body become inflamed. ...

Kawasaki disease: MedlinePlus Medical Encyclopedia Q

www.nlm.nih.gov/medlineplus/ency/article/000989.htm

Kawasaki disease occurs most frequently in Japan, where the disease was first discovered. In the United States, after congenital heart defects, ...

Kawasaki disease, form of vasculitis Is Kawasaki disease contagious? Q

www.nhlbi.nih.gov/health/dci/Diseates/kd/kd_whatis.html

In Kawasaki disease, the walls of the blood vessels throughout the body become inflamed. The disease can affect any type of blood vessel in the body, ...

Kawasaki Disease - All Sections (printer-friendly)

www.nhlbi.nih.gov/health/dci/Diseases/kd/kd_all_ntml

In Kawasaki disease, the walls of the blood yessels throughout the body become inflamed. The disease can affect any type of blood vessel in the body, ...

Causes of Kawasaki disease

www.nhlbi.nih.gov/health/dci/Diseages/kd/kd_causes.html

The cause of Kawasaki disease isn't known. The body's response to a virus or infection combined with genetic factors may cause the disease....

Kawasaki disease PubMed Health Q

www.ncbi.nlm.nih.gov > Home > Diseases and Conditions

23 Nov 2009 ... Kawasaki disease occurs most frequently in Japan, where the disease was first discovered. In the United States, after congenital heart ...



- Tip #1: Carefully select search terms
- Tip #2: Limit the number of search terms
- Tip #3: Think of word variations and synonyms
- Tip #4: Identify alternative terms
- Tip #5: Pay attention to the URL's
- Tip #6: Filter your search
- Tip #7: Discover the new features from Google



Three factors in any web search

- •1 Google
 - Collecting, ranking
- 2 Websites
 - Quality, organization, visibility
- •3 You
 - Search terms, queries, evaluation

