

S4 : Watch on rare disease information

There are many information sources which can help you keeping up with the latest news on rare diseases : newspapers and other media, scientific publications, databases, health agencies, organizations,...

As you will never have time to search for the whole information you need, you may use three main ways to make a watch about it : setting up a personalized section on Google News, receiving email alerts or subscribing to RSS feeds on Google News or PubMed

To manage your alerts on Google News and PubMed (store, modify, delete), you need to create accounts on their websites

To create your Google account, click Sign in, then Sign up for a new Google account, enter the required information, and accept the terms of service.

On Pubmed, click Sign in, then "Register for an account"; enter the required information : choose your user name, your password and give your email address, if you want to receive alerts through emails. Click Register.

S4.1 Setting up a personalized section on Google News

When you run a search on Google, the results are ranked according to more than 200 criteria including freshness of the information. However, as most Web pages are not dated, Google is not effective to separately identify recent documents on this Web menu.

That's why Google created a specific service, Google News, to provide users with an easy access to the latest information on various topics.

More than 70 regional editions are available in different languages. A drop-down menu selects the preferred edition, for example in the UK, or in the US.

Google News is a news aggregator : articles are collected on thousands of sources all over the world through computer programs, grouped by similar stories, automatically ranked, without any human intervention, according to characteristics such as location, freshness, relevance, and classified in eight standard sections including Health.

As the Health section displays general information on various health topics, it is helpful to customize it by creating a personalized section fit to your needs.

First connect to your Google account////. It allows to have your personalized sections saved and displayed every time you connect to Google News.

To create a section providing you with the latest news on Prader-Willi syndrome, click the Personalize button on the Google News home page, type your search terms in the field following the standard sections, click on Plus, then Save.

Your customized section is now displayed in addition to the standard sections on the left menu. Click the link Prader-Willi syndrome to display the related information.

If you want to delete this new section, click the Personalize button, then the trash can icon corresponding to Prader-Willi syndrome, and Save.

S4.2 Receiving email alerts

Alerts include specialized newsletters, alerts on new articles from electronic journals, and e-mails from various sources providing you with updates based on specific queries.

Newsletters published by public organizations, associations, databases,... are released on various frequencies and contain information concerning the topics covered by the website.

OrphaNews Europe is the electronic newsletter of EUCERD, the European Union Committee of Experts on Rare Diseases, published twice a month and informing on the latest news on rare diseases, orphan drugs, research, policy,....

*Eurordis publishes a monthly newsletter in **7 languages** which focuses on news and events with a specific interest for patients and support groups.*

You also can subscribe to receive alerts on new articles published in a medical journal, like OJRD. Generally, you have to register first for this free service.

Alerts on specific keywords are proposed by Google and most databases like Pubmed.

Google alerts are emails automatically sent to you and including the latest Google News or new Web pages related to your search terms.

PubMed offers a similar service named MyNCBI, provided by the National Center for Biotechnology Information, and informing on the latest medical information.

Here is an example on Google News. Be connected to your Google account to save your alerts.

Then run a search with the terms you want to monitor, for example Fragile X syndrome. Then click the link at the end of the results page "Create an email alert for Fragile X syndrome". An alerts page is then displayed where you can select your options including the type of information you prefer and the frequency. Click Create alert.

You can Edit, that is to say modify or delete your alerts from this page or through your Google account and the link Manage your Alerts.

To perform a fine tuned query for your watch, you can refer to the section How to optimize your Internet search with Google.

On Pubmed, first connect to your account by clicking Sign in, then enter your user name, password, and Sign in

Run your search, for example on Behcet syndrome. Click the Save Search link under the query box. Validate or modify the name of your search. Click Save. You have two options.

*If you select **No thanks**, your search is saved on PubMed and you can access to it at any time.*

*If you select a **Yes** radio button, you will receive automatic emails including links to the new articles published on PubMed about behcet syndrome, at the frequency you selected.*

Click Save to validate your choice.

To check and manage your searches saved on PubMed, connect to MyNCBI. Clicking the name of the Pubmed search displays all the articles from the database; clicking the link corresponding to "What's new" displays, if any, the latest articles since your last connexion.

This page also allows to modify or delete all your saved searches

S4.3 Subscribing to RSS feeds

RSS stands for Really Simple Syndication. Web syndication means that a website content is made available on another website or on your own computer.

To make a watch, RSS technology is helpful as it automatically provides an Internet user with the latest information from a website without having to often connect to it. It is also a secure way because you need not release a personal email address on the Web.

The content delivered to your computer through RSS technology is called a feed. An orange icon is generally displayed on websites proposing RSS feeds.

RSS feeds prepared by a website are written in a coding language known as XML (eXtensible Markup Language) which needs softwares, called readers, translating it in readable language. These softwares are included in most browsers like Firefox or Internet Explorer. Many other readers exist including Google reader.

Here is an example for RSS feeds using PubMed.

First you have to be connected to your Google account to store your RSS feeds.

Then run a search on PubMed, for example, on tuberous sclerosis.

Click the RSS icon located under the Search box. A window is then displayed where you can confirm or modify the name of the RSS feed. Click "Create RSS", then XML. Select a RSS reader from the drop-down menu of the next window, for example Google and Click "Subscribe now", then "Add to Google Reader".

The latest Pubmed articles on tuberous sclerosis are displayed. Every new article will be added automatically at the top of the list.

You can modify, delete or just view your RSS feeds through your Google account and the link to Google Reader.

A very useful tool to identify medical RSS feeds is MedWorm, built on over 6000 medical sources classified in various categories in order to browse easily the different topics.

On Google News, run a search, for example, on cystinosis.

Click the link at the bottom of the search results page "Create an email alert for cystinosis". A Google alerts page is then displayed where you can preview the results and select your options including the type of information you prefer and the frequency. Select the Feed option in the "Deliver to" field instead of typing your email address like for an alert.

Click "Create alert", then Click on Deliver to Google Reader

As it is specified, it might take some time before new items pop up concerning cystinosis.