

Rare Disease Video Portal

Carlos Luis Sánchez
Bocanegra

Luis FernándezLuque

“The best way to predict
the future is making it”





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- 0.2. RD Video portal
- 0.3. Analysis & Deployment
- 0.4. Results & conclusions

Rare Disease

Who

Any disease affecting fewer than 200,000 are considered rare. There are nearly 7,000 such diseases affecting nearly 30 million affected persons. We also think that here represent all patients and families affected by rare diseases.

We can find patient-driven alliance of patient organisations representing more than 469 rare diseases patient organisations in over 45 countries.



Rare Disease Day



Rare Disease

Needs

- **Affordability**
- **Access to specialist**
- **Access to therapies**
- **Comparative Effectiveness research**
- **General recognition of rare disease**

Some of this needs can be resolved by joining this families and patients together and promote the communication, Youtube help in this way to find this needs.



Rare Disease Video Portal (RD Video)

Rare Disease Video Portal (RD Video Portal) is a Portal web were display all possible and existed videos using Youtube API.





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RD Video Portal

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Rare Disease Video Portal

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RD Videos

Popular videos



Title: Albinism Fellowship LifeTech - Edition 2 - A first look at the Apple iPad



Title: Albinism Fellowship LifeTech Edition 3 - Doro 332, Amazon Kindle 3 and BigNames for iPhone



Title: Joubert Syndrome



Title: Passing the MD-CARE Act (Part 1 of 2)



Title: Always remember...



Title: Céline Dion marks 50th Anniversary of Canadian Cystic Fibrosis Foundation

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Video Rare Disease portal supported by Northern Research Institute (Norway)



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Top rated videos

This page is a demonstration of VotingAPI's integration with the Views module. It's set up to display nodes sorted by percentage ratings, the style used by Fivestar module.

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 <p>Title: "Living Longer with CF" Workshop part 2 of 7 Rating: ★★★★★</p>	 <p>Title: CFF CEO remarks on 2008 progress Rating: ★★★★★</p>	 <p>Title: Always remember... Rating: ★★★★★</p>
 <p>Title: Olympic Gold Medalist Films Advocacy/Awareness PSA Rating: ★★★★★</p>	 <p>Title: Tum EB Hope Rating: ★★★★★</p>	 <p>Title: PAIGE AT THE NIH Rating: ★★★★★</p>
 <p>Title: Canadian Cystic Fibrosis Foundation celebrates 50 years of progress Rating: ★★★★★</p>	 <p>Title: "Hemophilia Show" presented by the American Health Journal and HF Healthcare PART 3 Rating: ★★★★★</p>	<p style="text-align: center;">Strabismus</p>  <p>Title: 2008 Conference Session - Vision in Albinism - Structure and Function Rating: ★★★★★</p>

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Title: Volunteer Today: Pass the Passion



Title: Vertex Update: Bob Beall and Frank Accurso talk



Title: Vivre avec le syndrome Muckle Wells (CAPS - Cyropyrim Associated Periodic Syndromes)



Title: Vesna Skulic - Croatian Association for Rare Diseases



Title: Vitaly Matyushenkov, Children with SMA, Ukraine



Title: Vidricq Cursaru (Myeloma Euronet Romania) reacts to PlayDecide



Title: Victory



Title: vwdAwarenessVideo.wmv



Title: Vote today for more tomorrows



Title: Votre équipe de soins : unis pour votre bien-être

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Video News: Disease portal supported by Bertha and Wellcome Institutes (UK news)



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Video News: Disease portal supported by Barthelemy Research Institute (Barney)



RD Video Portal

Video display



Your vote could mean \$1 million for Duchenne research!

Vote on Facebook: <http://apps.facebook.com/chasecommunitygiving/charities/301212>

Duchenne muscular dystrophy is the most common, lethal, genetic illness of childhood. It is a progressive muscle disease that robs young men of the ability to walk, the ability move their arms, & their independence. Duchenne is 100% fatal.

Approximately 60% of Duchenne cases are inherited, while the other 40% are due to a spontaneous mutation. This means that anyone can have a child with Duchenne.

PPMD has a singular goal: to end Duchenne. No young man or family should have to endure the heartbreak of this devastating disorder. We began as a small group of parents & grandparents sitting around a table wondering how to increase funding into Duchenne research. Our grassroots origins, parent-led focus & passion help us move quickly & strategically. Winning the Chase Community Giving contest would significantly increase our ability to move Duchenne research forward & leverage more funds for similar programs.

Winning also reinforces with our families, friends & followers how vital their help is in our fight to end Duchenne. PPMD knows that finding a cure is not an easy job. It is not one that will be tackled by one researcher, one organization or even \$1MM, but rather the efforts of an entire community. Nothing is impossible.

Our race is against time. Every day we lose at least two young men to Duchenne. \$1MM buys us time which is everything for these boys.

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Only in the category(s):
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 rare

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Analysis & deployment

Youtube API

Youtube open it access through Youtube API, there we can recollect all metadata for exploring videos an mix with other platforms



Analysis & deployment

Drupal CMS

Drupal is a Content Management System is recommended for most new websites. A large number of modules and themes are already available for it.

Its adaptability and great numbers of modules give to developers big flexibility for create adapted frameworks for deploying with a minimal effort.



The screenshot shows the 'Blocks' administration page in Drupal. Red dashed boxes and arrows highlight various regions and the 'Select Region' dropdown menu. A red arrow points to the 'Operations' column with the text 'Click here to specify pages to display block'. Another red arrow points to the 'Region' dropdown menu with the text 'Select Region'.

Various regions of a Drupal page

Click here to specify pages to display block

Select Region

Block	Region	Weight	Operations
Navigation	crone2	0	configure
User login	Left Sidebar	0	configure
Disabled			
Meta tags	crone2	0	configure
Recent comments	crone2	0	configure
Search form	crone2	0	configure
Syndicate	crone2	0	configure
Top Menu	crone2	0	configure
Who's new	crone2	0	configure
Who's online	crone2	0	configure



Analysis & deployment

Crawling videos

- Get 379 videos
- From 12 channels of Youtube
- AlbinismUK
- CCFFadmin
- CysticFibrosisUSA
- Eurordis
- HFHealthcare
- MoreThanHemophilia
- NHFvideo
- NOAHAlbinism
- ParentProjectMD
- Rarediseaseday
- Raredisorders
- WFHcommunications



Analysis & deployment

Infrastructures

We use Taskfreak project management and subversion for control of version.

Taskfreak! Carlos Luis Sánchez Bocanegra
mié 01 jun 2011 18:59:26 CEST

Task View Manage My Tasks | All Users | All Users | All Contexts

	Project	Title	User	Deadline	Com.	Status	
23	HealthVideos	Check Diff functionality on subversion	Carlos Luis	08 Feb 11	1	🔴	🗑️
1	HealthVideos	Sprint meeting: Health videos status	Luis	10 Feb 11	2	🟡	🗑️
1	HealthVideos	Search engine does not work correctly	Carlos Luis	18 Feb 11	5	🟡	🗑️
2	HealthVideos	First code for module review on Drupal	Carlos Luis	18 Feb 11	2	🟡	🗑️
3	HealthVideos	Preparando eclipse en mhs	Carlos Luis	18 Feb 11	2	🟡	🗑️
3	HealthVideos	Health Videos Alpha 1	Carlos Luis	18 Feb 11	1	🟡	🗑️
3	HealthVideos	Create library system	Carlos Luis	18 Feb 11	1	🟡	🗑️
3	HealthVideos	Translate into english	Carlos Luis	18 Feb 11	0	🟡	🗑️
3	HealthVideos	wiki job documentation	Carlos Luis	18 Feb 11	0	🟡	🗑️
3	HealthVideos	Subversion commit of alpha 0.0.1	Carlos Luis	18 Feb 11	1	🟡	🗑️
3	HealthVideos	Subversion alpha 0.0.2	Carlos Luis	18 Feb 11	1	🟡	🗑️
1	HealthVideos	Create a new drupal for Rare Disease video model	Carlos Luis	19 Feb 11	0	🟡	🗑️
1	HealthVideos	Select a theme style for ER drupal	Carlos Luis	19 Feb 11	1	🟡	🗑️
2	HealthVideos	HTML5 Video Adapt	Carlos Luis	19 Feb 11	3	🟡	🗑️
3	HealthVideos	Redirect to grid display	Carlos Luis	20 Feb 11	1	🟡	🗑️
3	HealthVideos	Status report and documentation	Carlos Luis	20 Feb 11	1	🟡	🗑️
1	HealthVideos	Introduce metadata	Carlos Luis	21 Feb 11	5	🟡	🗑️
1	HealthVideos	Sprint for status ER	Luis	21 Feb 11	2	🟡	🗑️
1	HealthVideos	Sprint HealthVideos	Luis	21 Feb 11	2	🟡	🗑️
1	HealthVideos	Correct fields Youtube API Drupal field Assignment	Carlos Luis	21 Feb 11	2	🟡	🗑️
2	HealthVideos	Template + design	Luis	21 Feb 11	3	🟡	🗑️
3	HealthVideos	Correct date information and user name on display one video	Carlos Luis	21 Feb 11	1	🟡	🗑️
3	HealthVideos	AddThis upload on mhs	Carlos Luis	21 Feb 11	0	🟡	🗑️
4	HealthVideos	Design of the website	Carlos Luis	21 Feb 11	4	🟡	🗑️
1	HealthVideos	Install Marinelli Theme on ER.	Carlos Luis	22 Feb 11	0	🟡	🗑️
1	HealthVideos	Delete all facebook & twitter connect	Carlos Luis	22 Feb 11	0	🟡	🗑️
1	HealthVideos	List panel related/popular View	Carlos Luis	02 Mar 11	0	🟡	🗑️
1	HealthVideos	Sprint meeting	Luis	02 Mar 11	2	🟡	🗑️
2	HealthVideos	Getting a better Search engine	Carlos Luis	02 Mar 11	0	🟡	🗑️
3	HealthVideos	Related videos / Videos by Channel	Luis	02 Mar 11	1	🟡	🗑️
3	HealthVideos	Change theme for a similar skin like wiki	Carlos Luis	02 Mar 11	0	🟡	🗑️
1	HealthVideos	phpmyadmin in mhs problems	Luis	03 Mar 11	1	🟡	🗑️
1	HealthVideos	Pr ext Meeting	Luis	04 Mar 11	1	🟡	🗑️
1	HealthVideos	Get an stable version for bb4 to ER	Carlos Luis	04 Mar 11	1	🟡	🗑️

zotero YSlow



Analysis & deployment Infrastructures

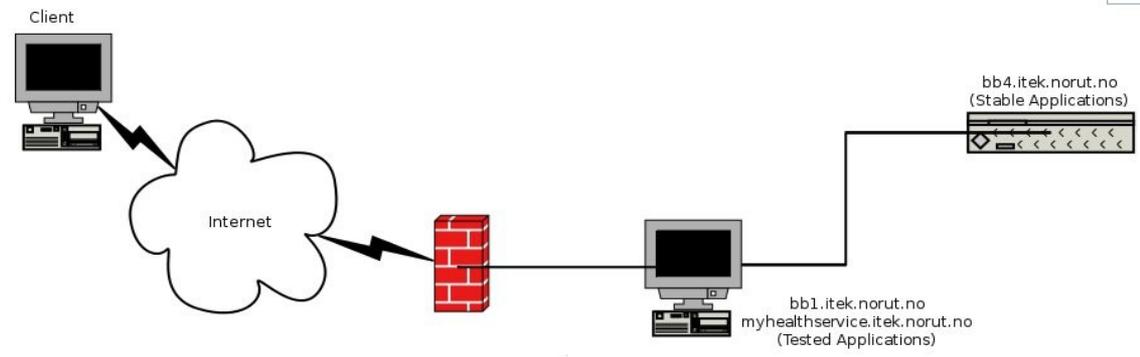
We use dokuwiki knowledge management.

System

Design

Edit

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•Youtube embed on Drupal
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•Standardization
•Command Folder
•key Keychain
•1st option
•2nd option



Port

- **myhealthservice or bb1:** 80, 443 (ssl), 8080 (tomcat), 8081 (tomcat), 22 (ssh), 110 (pop), 143 (imap), 25 (smtp).
- **bb4:** 80, 443 (ssl), 8080 (tomcat), 22 (ssh only intranet), 110 (pop), 143 (imap), 25 (smtp).

Edit

Details to consider

- System considerations

Edit

Applications

Edit





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Results & conclusions

- Strength
 - The crawling take no more than 30 seconds to recover the channels.
 - Drupal flexibility make more easy the adaptation of RD Videos -> Commodities on Drupal.
 - Ajax objects in some modules of drupal make the portal comfortable -> usability.
- Weakness
 - PHP languages need to improve for a real MVC framework.
 - Drupal has a complex way for a obsolete objects.
 - Drupal will need to promote on 7 versión.
 - Complete accesibility: not only video html compliance.
 - Better design.



