

HELLO

Using Social Media For RAREdisease

RareConnect **Social Media** Workshop
Brussels May 23rd 2012

Who Are We?



National **Batten Disease**
Charity **of Ireland**

CHY 19226

Beefor**Battens**.org

About Us.....

**Founded: March
2010**

**by Tony & Mary
Heffernan**

following the diagnosis of
both their children..

**Saoirse &
Liam**

with Batten Disease!



We had some thinking to do!

which led to a few questions...

what are we trying to do?

who are we talking to?

where do we say it?

how do we do it?

The Answers Would Become Our
Objectives.....

Bee for Battens Objectives

- Care and support
- Advance the education of the medical profession about Battens Disease
- Promote research into the management of Battens Disease
- Lobby Government
- Bereavement Support

Marketing 101 (STP)

- **Segmentation**
 - Families with Rare Disease
- **Targeting**
 - Irish Families initially
- **Positioning** – Source of support, knowledge and research

What Will Work ? Social Media Content

Content - Exciting & Engaging Topics

Conversation - Open Forum Debate

Consult - Ask Followers For Their Opinion

Creative - Be Innovative With Ideas

Collaboration - Work With Others Openly

In general, we found it very helpful to understand our audience and try to ensure that our messages which we are sending are interesting to our followers.

We setup up our identity **consistently** on



& the **public** started to **engage** with us **VERY QUICKLY**


Suddenly **Bee for Battens**

start to become a

“Brand”

Search Engine Optimisation

Web Images Videos News | More ▾



About 65,500 results (0.11 seconds) enhanced by Google

Web Images Videos News **Videos** More ▾

Ads

Batten Disease treatment | unistemcells.com
www.unistemcells.com/
treatment for **Batten's Disease** treatment for NCL

Battons | Ask.com
www.ask.com/Battons
Search for Battons Q&A Battons

Web results: Definition of **battens disease** by TheFreeDictionary.

About Battens Disease - The Facts
<http://www.beeforbattens.org/battens-disease.php>
Early symptoms of **Batten disease** (or NCL) usually appear in childhood when parents or doctors may notice a child begin to develop vision problems or seizures ...

Bee for Battens - The Irish campaign to raise awareness and support ...
<http://www.beeforbattens.org/>
Bee for Battens - The Irish campaign to raise awareness and support those affected by **Battens Disease**.

About Bee for Battens
<http://www.beeforbattens.org/about-us.php>
Battens Disease is a rare neuro-degenerative condition that affects babies, ... Tony and Mary Heffernan's daughter Saoirse was diagnosed with **Battens Disease**, ...

World Batten's Disease Awareness Day Ireland - Bee for Battens
<http://www.beeforbattens.org/blog-read.php?id=57>

[http://search.conduit.com/Results.aspx?q=battens diseas...78&SearchSource=15&SearchType=SearchVideos&SSPV=EB_SSPV](http://search.conduit.com/Results.aspx?q=battens+diseas...78&SearchSource=15&SearchType=SearchVideos&SSPV=EB_SSPV)

Find: Next Previous Highlight all Match case



Supporters were **literally** falling out of the sky!

But what is **Batten Disease**?

You Could **Say**

Its a Fatal Neurological (Brain) Condition
That Predominately Affects Children

& Causes:

Blindness

Seizures

Removes ability to walk / talk / eat etc..
or you could say nothing & just watch....

You**Tube**... A True Story By **BeeForBattens**

A true story by Bee for Battens



thank you !

JOIN US &

Bee the difference!



Bee For Battens .org

THE SAOIRSE FOUNDATION

