

Using Social Media For RAREdisease

RareConnect Social Media Workshop Brussels May 23rd 2012

Who Are We?













National Batten Disease Charity of Ireland

CHY 19226

BeeforBattens.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











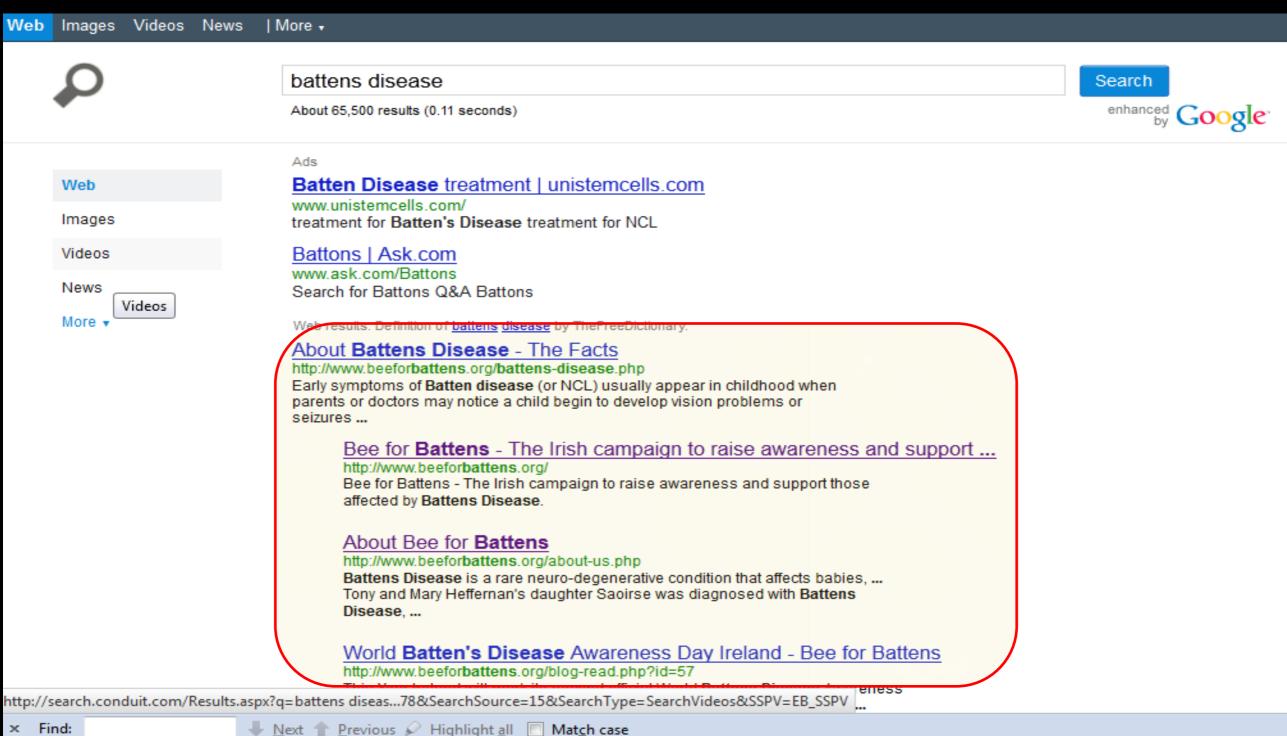
& the public started to engage with us VERY QUICKLY

Suddenly BeeforBattens

start to become a

"Brand"

Search Engine Optimisation





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....

YouTube... A True Story By BeeForBattens

A true story by Bee for Battens



thank you!

JOIN US &

Bee the difference!











