Is it time to "Start-Up" again?

A Patient Organization Case Report

Claudia Crocione

HHT Onlus

State of the Art 2011

After 7 years of "Activity":

Mission	**UNCLEAR**
Action Plan	**First come First Serve**
ROI	**A Mystery**
Organization	**Doctor & Hospital Centered**

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Translated in Figures

Item	Figures
Contacts in "database"	78
Budget	€5.800
Average age of Board members	72
Volunteers	None
Enthusiasm	Inexistant

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What Triggered the Change?

Me ;)

Allow me to tell me my story

Obstacles & Advantages

OBSTACLES

- They did not share my intuitions
- There were very few economical resources
- The Board felt the PO as a private property rather than a responsibility
- Doctors were extremely prevelant in the decision making process of the PO
- I did not have all the expertise needed
- There was so much to do I hardly knew where to start

ADVANTAGES

- I was starting from scratch
- They were grateful for my time
- I was the boss of myself
- I had the time
- I had some skills
- They were looking for enthusiasm (but didn't know it)

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If you love your organization and believe in your cause you make sure it can survive without you.

Foundation recipe:

<u>Basic Ingredients LIST</u>

- Identity

- Management/Method

- Communication

- Database

- Team

How I proceeded

- Start Up plan

- 3 year time and a specific budget

- Managed by me but involving all parties

- Reassured them they had nothing to lose

- Was very respectful of the role of the Board

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New Identity part one: Mission

"People born with HHT face great challenges that we help them overcome through faster diagnosis, local healthcare, overcoming solitude and finding a cure." (22 words)

A clear mission is paramount for:

- **Planning**

- **Communicating**

- **Engaging**

Effects: Board involvment and new prospectives

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New Identity: Branding

In NON PROFIT branding produces: fidelity, sense of belonging, attraction, authority

www.font-combinator.com
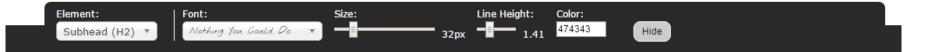
font-combinator.com

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A Web Typography Tool

This tool has been built to allow previewing of font combinations in a *fast, browser-based* manner. There have been numerous printed books through the years that allowed a designer to put a headline font next to a body font, and this is an attempt to recreate that for the web.

Directions: You can edit any of the type on this page in order to preview any particular text. In the controls at the bottom, select the element you want to modify, and then *play!* You can change the font, size, line height and color of an element, as well as hide an element altogether.

Element:	Font:	Size:	Line Height:	Color:	
Subhead (H2) ▾	Nothing You Could Do ▾	32px	1.41	474343	Hide

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Professional Pro-bono pictures

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More pics

Effects: Board & Family excitment and involvement.

Authentic patients – sense of belonging

Management
Mission

Action Plan & Budget:

- *They go together*

- *Developed end of year & approved before February*

Return on investement:

Periodical measuring of results. (surveys, meetings, project management)

Effects: responsibility rather than property.

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PROGETTO DI SPESA 2017

Settore di operatività	capitolo di costo	specifiche	qnt	ulteriori specifice	Preventivo
AMMINISTRAZIONE					
	Commercialista		1 anno		510
	Conto Bancario		1		250
	Conto Postale		1		85
	Assicurazione				640
				Sub Totale	**1485**
DIRETTIVO e COORDINATORI					
	Rimborsi Viaggi direttivo per Assemblea Iscritti				1000
	Spese vitto assemblea iscritti				350
				Sub Totale	**1350**
COSTI GENERALI					
	Cancelleria				100
	Spedizioni				100
	Manutenzione e acquisto apparecchiature				800
	VIAGGI e rimborsi				1000
	SOFTWARE				500
				Sub Totale	**2500**
FUNDRAISING & COMMUNICAZIONE					
	5XMILLE	ristampa materiale	10000		90
		costi di spedizione	1000		400
		lettera accompagnatoria	1000		0
	maglie HHT e cappellini				857
	BOLLETTINI POSTALI		2000		60
	Bomboniere Solidali	Progettazione grafica			150
		Bomboniere			500
		pagina ordini sito			150
	Grafica Varia durante l'anno				200
				Sub Totale	**2407**
COLLABORAZIONI					
	Claudia Crocione	Da suddividere nelle varie attività			19.200
				Sub Totale	**19200**
Mission Associativa					
	Diffusione Consapevolezza	spese vive attività regionali		rimborsi/stampe ecc...	2000

Diffusione Consapevolezza	**spese vive attività regionali**		rimborsi/stampe ecc...	2000
	guida HHT a scuola		grafica e stampa	500
	premio tesi di laurea			0
Abbattere muro della Solitudine	**CAMP 2017**		sopralluoghi	400
			viaggi relatori	1000
			pasti relatori	1200
			albergo relatori	2000
			noleggio sale	1000
			spedizioni	200
			coffee break	700
			cartoleria	100
			grafica evento	400
			stampa programma	100
			spedizione programma	200
			Programma sociale	300
			Attività bambini	0
			varie ed eventuali	200
			rimborsi volontari vitto	500
			progetto giovani HHT 2017	7500
	Copyrighht (3 uscite)		posta target	400
			stampa 220 copie per 3 uscite	1200
		600	buste	100
	Sito	2	Hosting	350
	Help Line		costi telefonici	220
Servizi e Terapie in ogni regione	**Relazioni Pavia, Gemelli, Bari**		rimborso viaggi	400
Trovare una Cura				
	Uniamo	1	iscrizione	0
	HHT Foundation	1	iscrizione	0
	Eurordis	1	iscrizione	75
	HHT Europe	1	iscrizione	300
			viaggi presidente HHT Europe	0
			Sub Totale	**21.345**

Database
Mission + Management

Communication
mission + branding + management + database

Who are we talking or listening to?

Patients (all ages), Family members (all ages),

HCPs & Researchers, Supporters

What are we communicating?

information, events, celebration, needs, stories

How? (will depend on who and what!)

magazines, newsletters, website, blog, social media, brochure, events, mass media, help line, email, contact forms.

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Team

mission + branding + management + database + communciation

- **Mission:** the right people come to you
- **Branding:** they recognize you and they feel they belong
- **Managing:** you sustain their efforts
- **Database:** you record and remember them
- **Communication:** you make yourself interesting and you celebrate your volunteers.

And then?

We developed another 3 year action plan this time based on our MISSION:

- Increasing levels of diagnosis

- Efficient care close to the patients

- Overcoming solitude

- Finding a cure

The results in figures

Item	Figures 2011	Figures 2013	Figures 2017
Contacts in "database"	78	925	1392
Budget	€ 5.800	€32,000	€52,000
Average age of Board members	72	48	42
Volunteers	1 (me)	14	23
Enthusiasm	Inexistant	Soaring	Skyhigh
Training	None	3 attendees	5 attendees
Fundraising	None	Volunteers	Volunteers
Patient Centered Activities	0	Most	All
Staff	0	1	1

You can make it happen

Questions?

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