

Virtual interaction with real patients

EMA PCWP/HCPWP Workshop on Social Media

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Fondazione Telethon

FONDAZIONE



Facts and figures about the Telethon Foundation

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Our mission

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Fondazione Telethon is a major Italian **charity focused on rare genetic diseases**. Founded in 1990 by a group of muscular dystrophy patients, its mission is to **advance biomedical research** towards the cure of all the rare genetic diseases, otherwise neglected by major public and private investments.

The ultimate goal is to **make therapies available to all patients in need**. To achieve this goal FT funds mission-oriented research strictly selected through a **peer review evaluation process** and encourages collaborations between private and public institutions in order to develop therapies from the results obtained.

Fondazione Telethon relies on donations from the general public through major **fundraising events** (such as the annual television marathon) and various fundraising initiatives held throughout the year. **Accountable fund management and careful expense monitoring** are performed to fulfill its promise to patients and to the donors who continue to support its mission.

[WATCH OUR MISSION](#)

A Track Record of Excellence

FONDAZIONE



**2,570
Research Grants**

We support only top,
internationally
competitive projects,
through
highly selective peer
review conducted by a
prestigious international
Committee.

**Over € 451 M
Invested**

**1,556
Funded scientists**

**Over 20
Therapeutic strategies
at the clinical or
pre-clinical stage**

**ONLY THE BEST BASIC
AND CLINICAL
RESEARCH.**

**470
Rare Diseases Studied**

**10,222
Scientific Publications
(1990-2014)**

A network of Friends

182 Patient Organisations decided to join **the Friends of Telethon network** in order to have access to:

- Information and scientific advice
- Training events
- Empowerment pathways
- Advocacy actions
- Help in connecting people and creating a Patient Organisation

The initiatives are led by the Telethon Patient Care Unit and are often developed in collaboration with **Uniamo**, the Italian Federation of People living with a rare disease.

The Digital strategy

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The assets of the digital communication

**Disseminaton
- constant
presence**

Raising awareness on RD,
dissemination of scientific
topics, storytelling

Versatility

Possibility to use the different
platform and tools according to
the targets

Low cost

Low adv and digital
PR investments.

Interaction

All the campaigns have a strong
impact on stakeholders'
community engagement, that is
the asset to join a wider
community, especially the people
that don't feel yet involved by the
problem

The objectives of the digital communication

- **Raising awareness and brand positioning**
- **Supporting fundraising activities and marketing programs**
- **Creating a real patients community with Fondazione Telethon's stakeholders**

 **Stakeholders: people living with RD and their families, patient organisations, researchers, doctors**

- Parents of children who aren't affected by a RD 
- Donors and e-buyers
- Volunteers
- Students 
- Fondazione Telethon employees

After the last three years spent in consolidating the main target, we're approaching a wider but contiguous target, the parents of children in school age that are very active on social media (FB especially) and that are very sensitive to our mission. This target has been approached through specific actions and campaigns:

- #backtoschool campaign
- DRTV (direct response television) dedicated to parents
- the tv marathon shortfilms focused on parents

The digital Platforms

Fondazione Telethon has set **5 digital assets** :

- The website
- The newsletter
- Social media
- Digital PR
- Intranet

Overview Social media / website

Facebook 240.000 fans, + 38% from June 2016

Twitter 74.000 followers, + 38% from June 2016

YouTube 717 videos, 2.521 subscribers, 3.200 millions views

Instagram 8.818 followers, + 100% from February 2016

And...

newsletter subscribers: 39.448

telethon.it website:

1.246.860 unique visitors/year

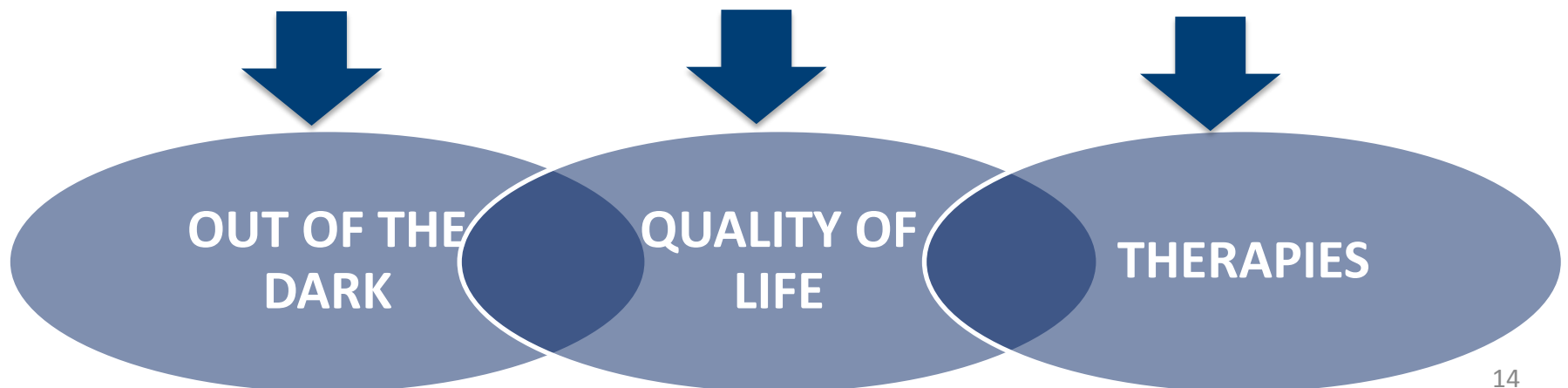
Unique page views **2.837.591**

Total page views **3.831.866**

The Contents of storytelling

- The problem: genetic diseases affect 250M people in the world
- Our answer: raising funds to foster excellent research
- The results: diagnosis, therapies, technical aids, QoL

OUR STORYTELLING STRONGLY RELIES ON *USER GENERATED CONTENTS* THAT ARE COLLECTED ACCORDING TO 3 NARRATIVE LINES



The tools for storytelling

All the contents are collected and chosen according to a coordinated **EDITORIAL PLAN** that is declinated for each different social media.

The tools:

- Text
- Video and Photos
- The live streaming (Facebook live, Periscope)
- Q&A session



The editorial plan for each social media

EMOTIONAL STORYTELLING



Contents

- Storytelling (with UGC)
- News about research and FT activities
- Volunteers' storytelling
- Everyday life, celebrations (father's day, mothers'day, Xmas)

Actions

- # Special campaigns
- Private messages to engage the community collecting UGC.
- VIPs, bloggers and influencers call to action
- Chat and mentions; institutions - VIP
- Digital PR

04/11/2016
New target: Parents

NEWS AND LIVE



Contents

- News about FT research
- Live from special events
- Information on PO's events
- Volunteers, donors and patients stories (with UGC)
- Every day life, Anniversary celebrations (fathers's day, mother's day)
- Marketing products

Actions

- Contest # for users
- Engagement VIP/influencer
- Engagement private companies

New target : TV, radio, entertainment, music, information (journalists, bloggers, influencers)

THE BACKSTAGE



Contents

- tv telethon backstage,
- everyday life, celebrations (father's day, mothers'day, Xmas),
- Telethon marketing products

Actions

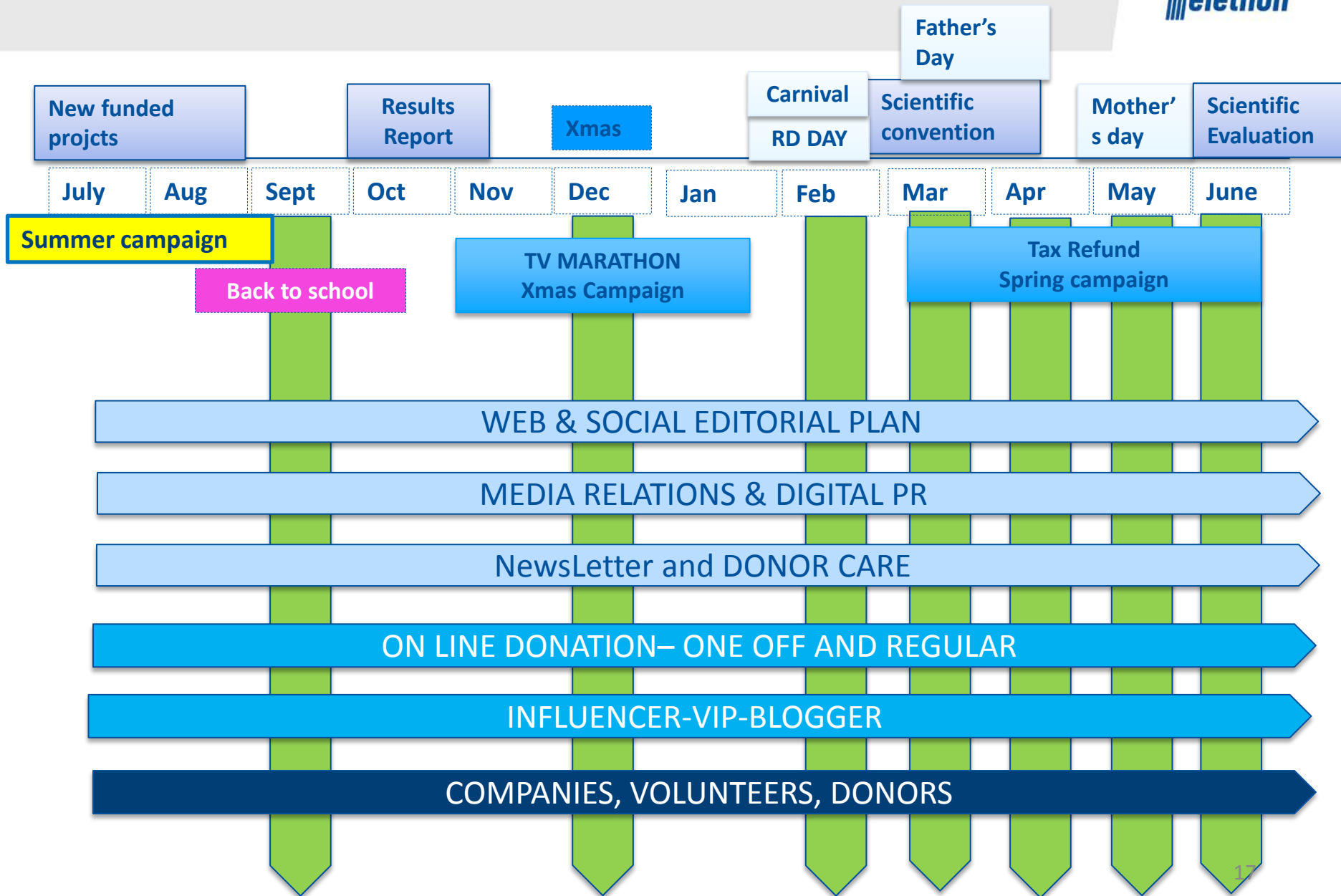
- Contest # for users
- Engagement VIP/influencer
- Engagement private companies

New target

- Young people (students)
- parents

The digital agenda/ campaigns

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THE MAIN CAMPAIGNS

2012- 2013 #ioesisto (#IDoExist)

2014 #ognigiorno (#Everyday)

2015

#backtoschool

#nonmiarrendo (#Idontgiveup)

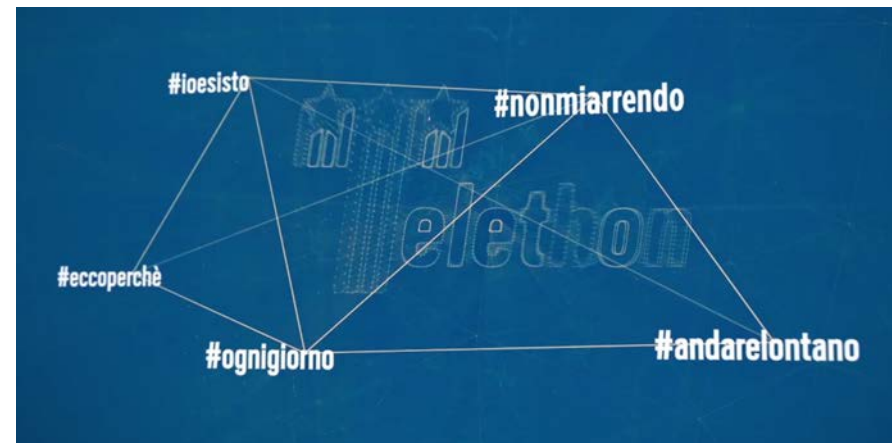
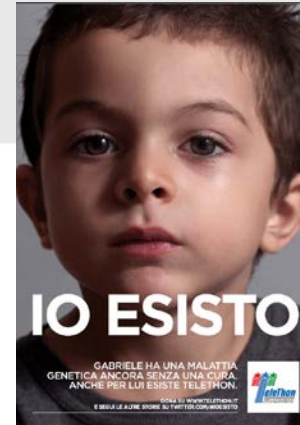
I can make my voice heard by many people,

I can come out of invisibility

I can make my disease more known

I can share experiences

I can communicate freely and
without embarrassment



Mother's and Father's Day

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Auguri a tutte le mamme!
#festadellamamma



Sono un papà e non mi arrendo.



Tommaso: waiting for gene therapy with the nurse Miriam



FONDAZIONE TELETHON
"Mi piace" aggiunto alla Pagina · 24 giugno ·

Caricamento... tato trattato con la terapia genica dell'Istituto SR-FIGET di Milano. Grazie a GlaxoSmithKline, Fondazione Telethon, l'IRCCS Ospedale San Raffaele (OSR), quella terapia è diventata un farmaco a disposizione di tutti. Ne parliamo lunedì (ore 15.30) presso la Presidenza del Consiglio dei Ministri. Segui l'evento con noi!

Mi piace · Commenta · Condividi

1.9 mila · Commenti più in vista

161 condivisioni · 69 commenti

Marisa Corrente Ciao Tommaso forza e coraggio vedrai che andrai lontano!!! Un grande abbraccio piccolo. ❤️
Mi piace · Rispondi · 25 giugno alle ore 15:52

Giuseppe Manenti Ciao tommaso ti faccio il piu bell augurio di ❤️ x la tua guarigione forza piccolo campione Tommaso ciao! 👍
Mi piace · Rispondi · 25 giugno alle ore 21:24

Eva lonni Ecco un altro esempio di dove finiscono i soldi!! Vorrei sapere adesso quelli che sanno solo lamentarsi dello spot tv e di quelli che parlano a sproposito dicendo che raccolgono soldi senza portare risultati cosa hanno da dire! Sarà una piccola goccia ma intanto è qualcosa!!!
Mi piace · Rispondi · 28 giugno alle ore 23:27

Cristina Leonardi Bello che sei Tommy! Devi essere sempre forte! Un grandissimo abbraccio ❤️
Mi piace · Rispondi · 25 giugno alle ore 21:38

Graziella Festari Grazie di esistere lun bacione Tommaso!!!

Scrivi un commento...

A special encouragement to Giulia, affected by osteogenesis imperfecta

FONDAZIONE TELETHON
"Mi piace" aggiunto alla Pagina · 23 giugno ·

Giulia ha passato un momento un po' difficile, perché «si era fratturata il femore ed ha tenuto il gesso per 30 giorni. Ma adesso siamo ripartiti alla grande!». E come ci racconta mamma Elisabetta: «Affronta la sindrome di Charge sempre con il sorriso. E questo suo sorriso è la nostra forza: ogni piccolo progresso che Giulia fa, con impegno e determinazione, è una grande conquista». Le mandiamo un bacio?

Mi piace · Commenta · Condividi

3,9 mila · Commenti più in vista

155 condivisioni · 380 commenti

Rosso Corallo Bella e coraggiosa! Ti mando un mondo di baci con tanto affetto! Un abbraccio alla mamma 🍷🍷🍷🍷🍷
Mi piace · Rispondi · 6 · 23 giugno alle ore 20:03

Maria Clemente Ciao Giulia , ti auguro tutto il bene di questo mondo, un bacione e un abbraccio forte forte
Mi piace · Rispondi · 5 · 23 giugno alle ore 20:46

Carlotta Guaitini Piccolina ti mando tanti bacini. ...ti auguro di continuare a fare progressi e continua a sorridere!
Mi piace · Rispondi · 3 · 23 giugno alle ore 20:01 · Modificato

Anna Caridi Bella Giulia !! Che coraggio !!! Sei una bimba dolcissima ! Un abbraccio e brava mamma !!!
Mi piace · Rispondi · 1 · 24 giugno alle ore 8:39

Maria Paola Feduzi Brava Giulia, sii sempre forte!! Un bacione a te e alla tua famiglia!!

Foto del diario · Tagga la foto · Opzioni · Condividi · Invia · Mi piace

Happy birthday Lara and Gaia!

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FONDAZIONE TELETHON
"Mi piace" aggiunto alla Pagina · 30 giugno ·

Oggi Lara e Gaia, le due dolcissime gemelline che affrontano la SMA II, compiono 6 anni! Questi sono gli auguri di mamma Laura: «State crescendo; avete appena frequentato l'ultimo giorno di materna. Ora per voi comincia un nuovo percorso di vita. Voglio dirvi che siete la cosa più bella che abbia fatto nella mia vita. Auguri!». Ora tocca a noi! Forza con i commenti!

👍 Mi piace · 🗨️ Commenta · ➦ Condividi

👍 🎉 🥳 4,6 mila · Commenti più in vista ▾

372 condivisioni · 725 commenti

Federica Muller Auguri ragazze !!!!...buona vita !!!!
Mi piace · Rispondi · 👍 1 · 30 giugno alle ore 15:24

Antonella Di Cola Buon compleanno bellissime
Mi piace · Rispondi · 👍 1 · 30 giugno alle ore 15:06

Storia Di Francesco augurissimi
Mi piace · Rispondi · 👍 1 · 30 giugno alle ore 19:48

Roberta De Stefani Auguri gemelline per il vostro compleanno e in bocca al lupo per il prossimo percorso scolastico, ma soprattutto un forte augurio nello sconfiggere la sma. Un abbraccio forte a voi e la vostra super mamma.
Mi piace · Rispondi · 👍 5 · 30 giugno alle ore 15:51

Bruno Biffi Tanti auguri bellissime lottare fino alla fine vedrete che con l'aiuto dei vostri genitori raggiungerete il vostro meritato traguardo un abbraccio
Mi piace · Rispondi · 👍 1 · 30 giugno alle ore 15:51

Scrivi un commento...

Foto del diario · Tagga la foto · Opzioni · Condividi · Invia · 👍 Mi piace

Vincenzo and the Paralympics Games

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FONDAZIONE TELETHON

"Mi piace" aggiunto alla Pagina · 11 settembre ·

Più forte della malattia di Charcot Marie Tooth, più forte dell'emozione dell'esordio! Alle Paralimpiadi Rio 2016 il nostro Vincenzo Boni ha conquistato il bronzo nei 50 dorso S3! Grande Vincenzo! Congratulazioni da tutti noi! #Paralympics #Rio2016 Riviviamo insieme la premiazione: <http://www.raisport.rai.it/dl/raiSport/media/Bronzo-per-Boni--Podio-92f2f48d-5533-4f0c-a256-1c129e8cf26e.html> — con Vincenzo Boni

👍 Mi piace 🗨 Commenta ➦ Condividi

👍❤️👏 1,8 mila

Commenti più in vista ▾

178 condivisioni

82 commenti



Vincenzo Boni Grazie amici!

Mi piace · Rispondi · 1 · 15 h



FONDAZIONE TELETHON Grazie a te! Bellissima soddisfazione! Grande Vincenzo!

Mi piace · Rispondi · 3 min



Pina Autilia D'Avino forza campione sei grande lo sport unisce tutti grazie per l'esempio che date

Mi piace · Rispondi · 1 · ieri alle 3:26



Maria Cosima Cavallieri Bravissimo campione.... Sei fortissimo non mollare....Vincenzo...

Mi piace · Rispondi · 1 · ieri alle 0:01



Adriano Ravaglioli Onore al nostro atleta per le soddisfazioni che ci ha procurato con il suo bronzo

Mi piace · Rispondi · 1 · 15 h



Ketty Capria Grande Vincenzo...la tua voglia di fare ,ha superato limiti e barriere!!!!👏👏👏

Mi piace · Rispondi · 1 · 11 settembre alle ore 22:45

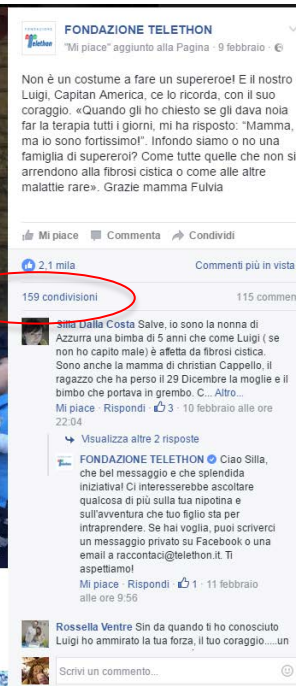


Scrivi un commento...



The Carnival

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Case study
#nonmiarrendo
(#idontgiveup)

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**#non mi arrendo
(#i don't give up)**

After affirming the existence of the rare disease patients (#I do exist), after emphasizing the everyday struggle and explaining why Fondazione Telethon can make the difference (#Every day), now the focus should be on the daily battles that rare patients have to face. Not only a claim, but a battle cry and a way of being, focused on their daily difficulties, as well as stating the trust to succeed together in curing RD.

The campaign strategy



The campaign included two main phases:

Approach – October/November 2015

Objectives: brand positioning and dissemination of the new hashtag that became familiar to the fanbase

Target: Telethon fanbase

Action: teasing

Launch – December 2015

Objectives: fundraising, engagement

Target: Telethon fanbase, prospects (parents)

Action: call to action to donate

5 institutional subjects (short films, photos and video produced by Fondazione Telethon) from the official fundraising campaign:

➤ In the Approach phase **they were used as a teaser** (trailer- half hidden covers)

➤ In the Launch phase **they were disclosed**

UGC (homemade videos, photos) from the stakeholders, donors, volunteers

MOTHER + CHILD

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**Per tutte le volte
in cui ci dicono che
la nostra missione è folle...**

Seguiteci per saperne di più...



#nonmiarrendo
perché insieme siamo più forti della malattia.

#nonmiarrendo
perché insieme siamo più forti della malattia.

CLAIM: BECAUSE TOGETHER WE'RE STRONGER THAN THE DISEASE

PATIENT+ RESEARCHER

FONDAZIONE



**Per tutte le volte
in cui ci dicono che la ricerca
sulle malattie rare è inutile...**

Seguiteci per saperne di più...

#nonmiarrendo

perché so che la ricerca è sempre al mio fianco.



#nonmiarrendo

perché so che la ricerca è sempre al mio fianco.

CLAIM: BECAUSE I KNOW THAT RESEARCH IS ALWAYS BY MY SIDE



**Per tutte le volte
in cui ci dicono che
la nostra missione è folle...**

Seguiteci per saperne di più...



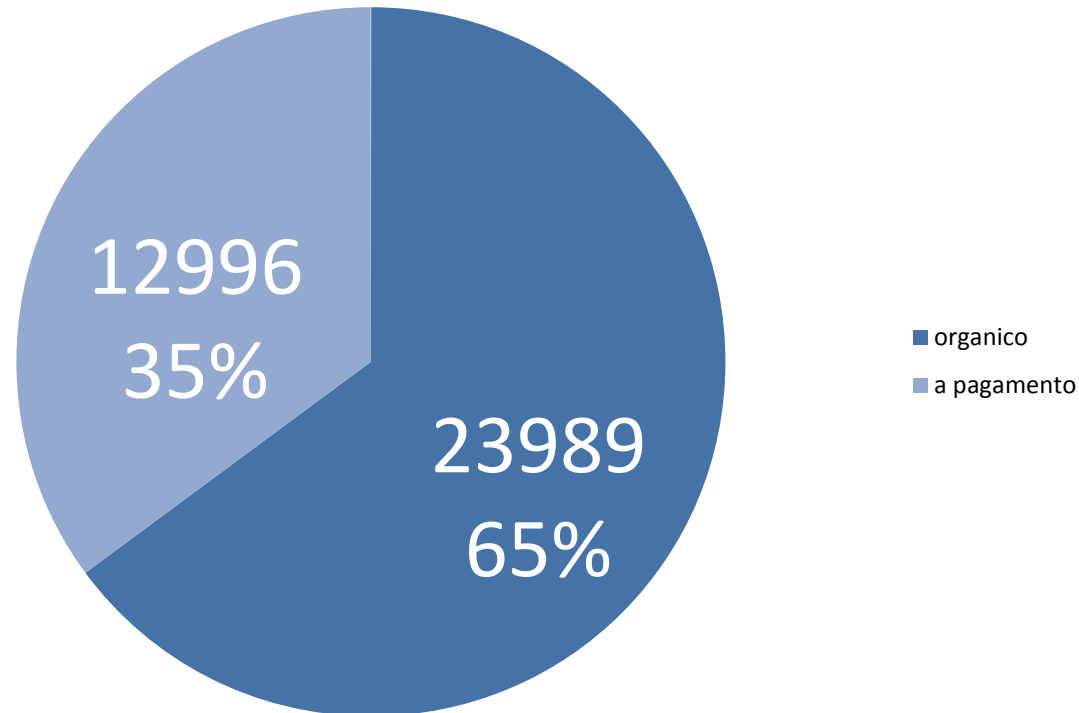
#nonmiarrendo
perché i miei genitori non l'hanno mai fatto.



CLAIM: FOR EVERYTIME PEOPLE SAY THAT OUR MISSION IS FOOLISH

New Facebook Fans earned in October-December '15

The Facebook organic activity allowed to achieve **65% increase in new fans**. There wasn't a specific aim to increase the fan base, hence it was a byproduct highlighting the brands' ability to engage Telethon's page fans.



VIDEO on Facebook

TOTAL REACH: almost 16 million users

The organic force of video contents contributed to generating 4.173.932 contacts (26% of total contacts). Federica's story is the first in the ranking of the total reach (over 3,980 millions).

Video	Data	Total Reach	Organic Reach	Total views	Unique views
Federica	10 december	3.980.476	1.308.654 (32%)	1.838.201	1.221.598
Emanuele	4 december	2.063.310	679.579 (32%)	988.826	727.189
Michele	25 november	2.400.833	664.480 (27%)	1.155.780	772.924
Giuliana	30 november	2.043.444	143.023 (7%)	1.019.567	637.456
Corale	14 december	1.864.115	280.672 (15%)	1.076.224	703.120
Emanuele 2	18 november	966.805	412.852 (42%)	352.220	298.616
Nina 2	4 december	1.198.434	196.105 (16%)	598.903	417.662
Nina	24 november	1.209.649	388.231 (32%)	497.575	379.169
Michele 2	20 november	100.341	100.336	19.101	17.718
TOTAL		15.827.407	4.173.932 (26%)	7.546.397	5.175.452

Reach gathered through the posts (not including the video) have increased 146% (organic) and 258% (organic+ paid) compared to the 2014 data.

The assets were: a coordinated editorial plan, advertising actions, Q&A and Live streaming.

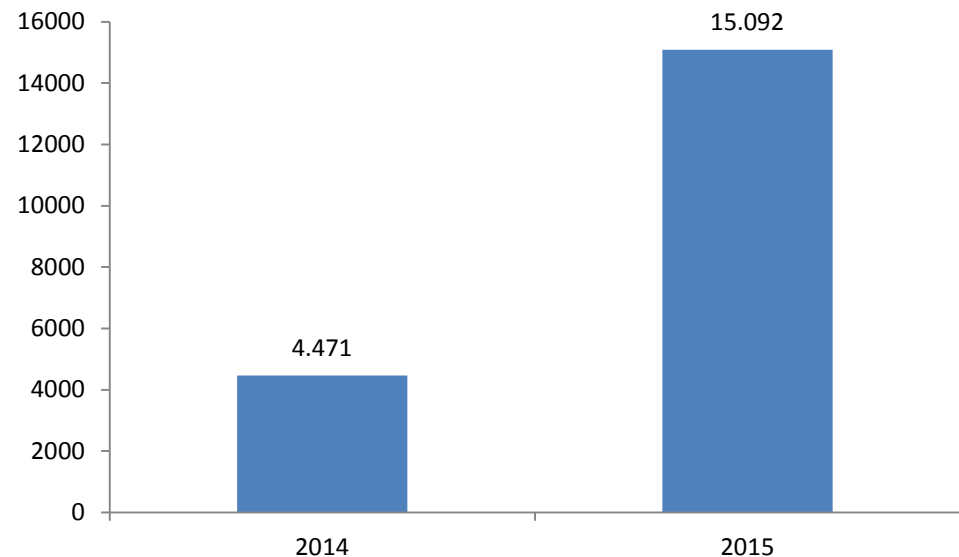
	Total Reach	Organic Reach
2014	4.536.383	3.647.815
2015	16.260.161	9.004.975
Difference	+258%	+146%

Engagement on Facebook

#idontgiveup campaign was a good way of increasing the daily Facebook fanbase engagement: we **tripled the daily users engagement** (people who interacted with comments)

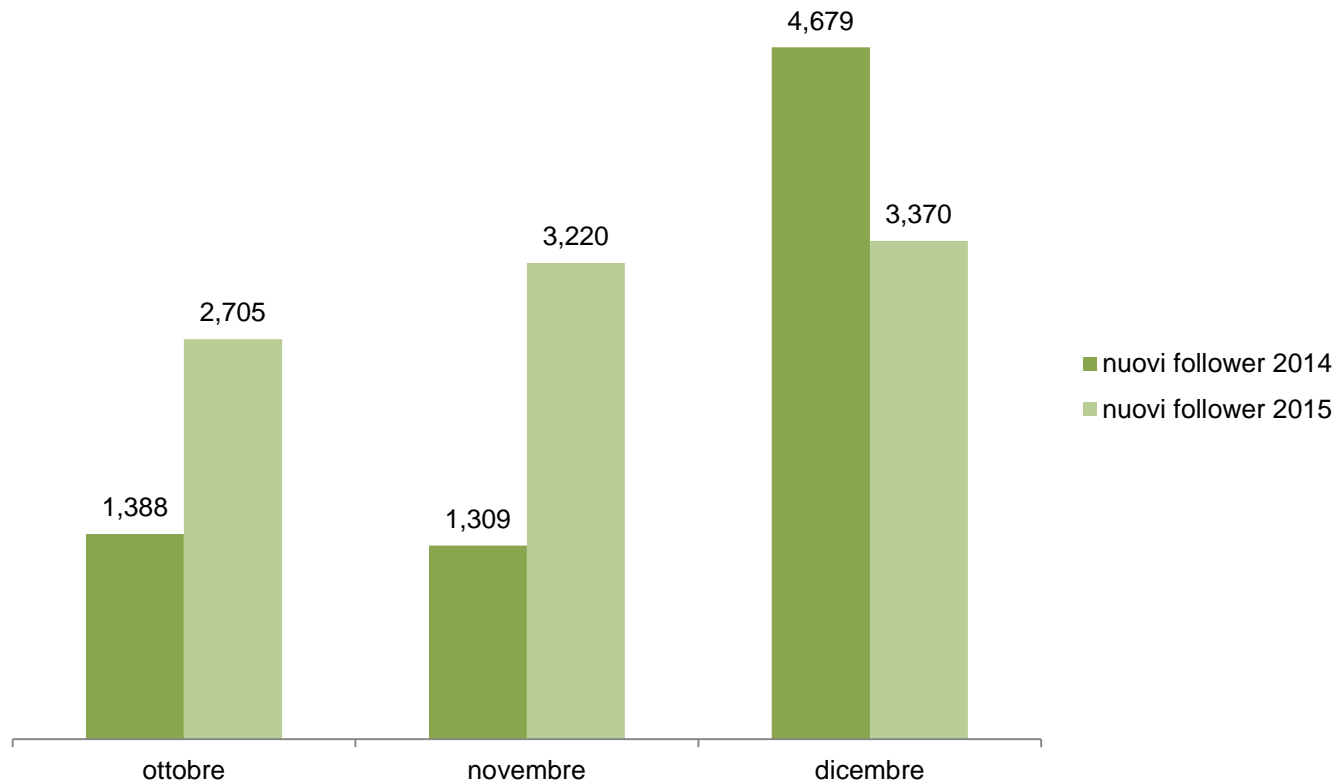
Three are the main reasons:

- **The consolidation of the FT fanbase** that has become more loyal and interactive, sharing our contents
- **The tv and web contents were more integrated:** FB constantly posted in real time what was happening on tv
- **Better moderation**



TWITTER: New followers

Compared to 2014, the growth on Twitter appears visibly smaller. Two are the main reasons: a general fall of the Twitter audience (-11% from May 2014 to May 2015) and, consequently, our editorial choice to focus more on FB and Instagram.



CONCLUSIONS

Sinergy:

Social media is a great asset to support our messages, especially during the tv telethon. **All the digital platforms should work coherently together** (graphic and copy)

Sharing:

People living with rare diseases are at the core of all Fondazione Telethon's activities, therefore the digital strategy is strongly based on **user generated content**: the content provided by patients are at the heart of Fondazione Telethon's storytelling strategy.

Planning:

All the contents are planned through a **strong editorial plan** alternating patients' stories, research updates, researchers' stories, patient organizations updates, volunteers' and donors' stories, fundraising call to actions.

Engagement:

- Not only towards the stakeholders, but also towards those **people who don't feel yet involved by RD**
- The patients are aware that they can support Fondazione Telethon's research by sharing their stories and experiences. The contents provided are an inexhaustible source of **interactions between families, researchers and clinicians**.
- **Virtual relations have become real friendships** between patient organizations and groups of volunteers located around the country.
- The participation in social media also allows FT to **share valuable information about research and quality of life**, contributing to the patients becoming more aware and informed.

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Instagram: Telethonitalia <https://www.instagram.com/telethonitalia/>



THANK YOU