

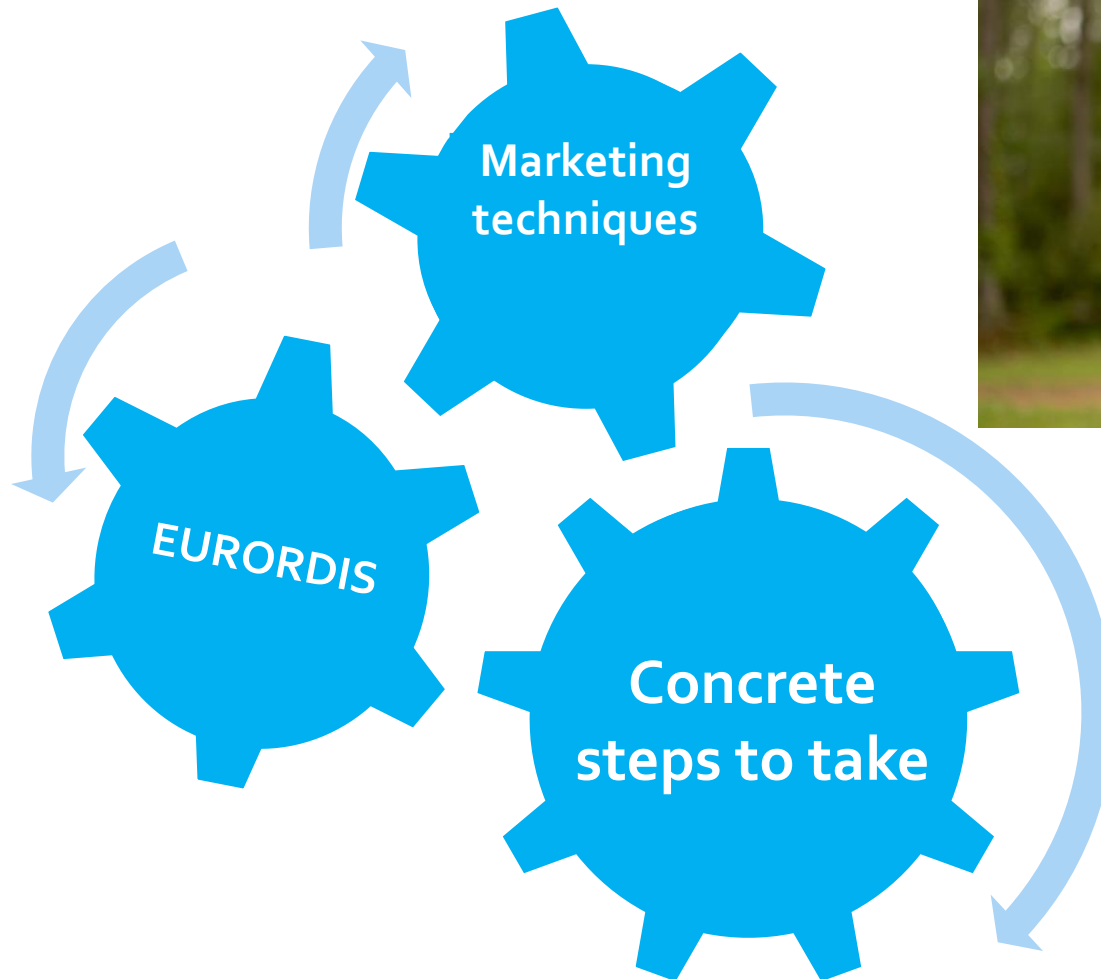
SMALL PATIENT ORGANISATIONS: COMMUNICATION

Creating a positive image and
impact

Lara Chappell, Communications Director,
EURORDIS



Me, myself and I speaking today...



Making a positive impact – simple steps!

- Low cost



- Little time



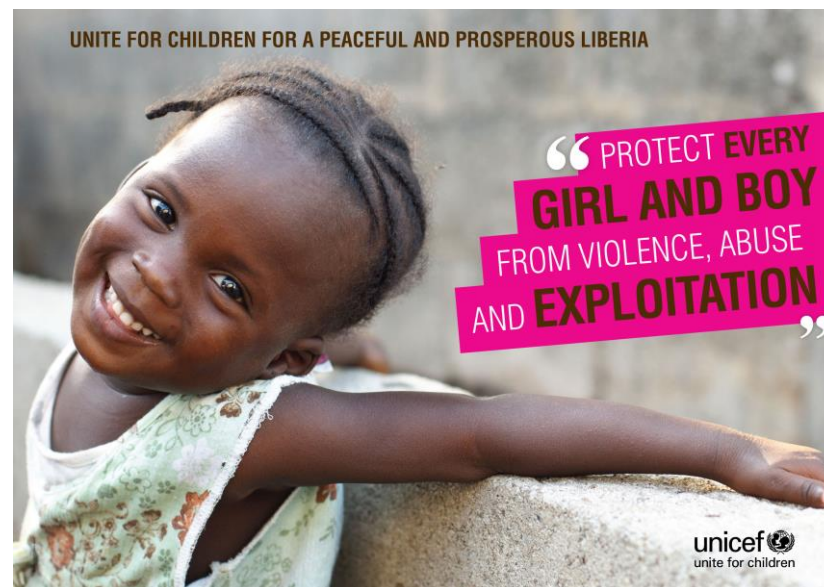
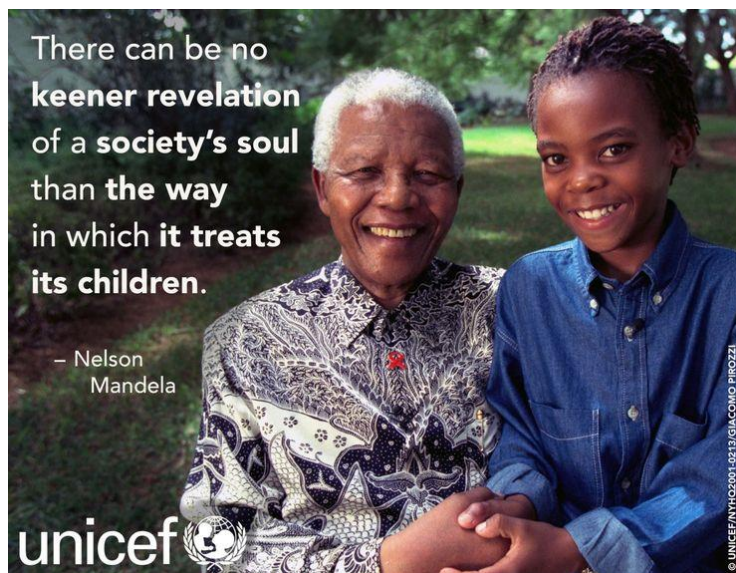
- Goal

Engaging people, making them feel good about their contribution and keeping them!

Why positive? UNICEF case study



More recent ads for UNICEF



People want to know their contribution is having a positive impact!

Topics

- Organisational identity
- Email responses and organisation
- Visual identity
- Social media



Organisational identity

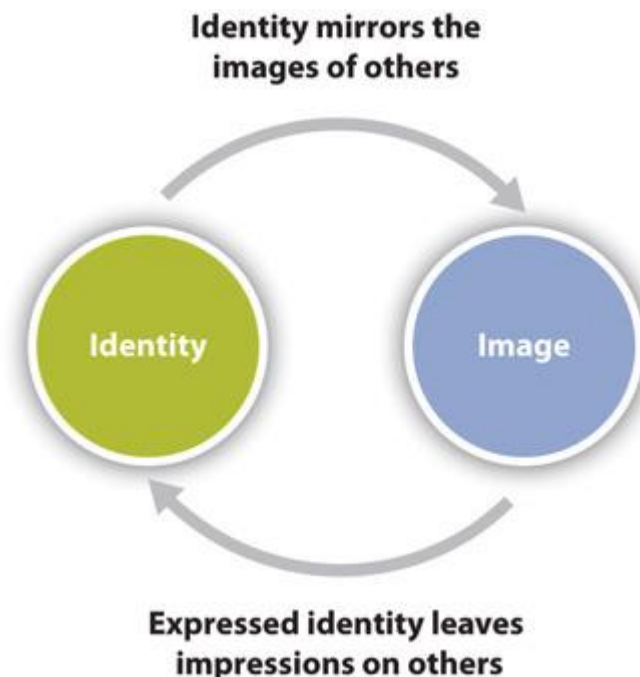
Organisational identity has been defined as what is central, enduring and distinguishing about an organization and reflects a combination of its:

Core values (what we stand for)

Distinctive characteristics

Unique value it creates for customers and society as a whole

Identity tends to be fixed while its manifestations are constantly changing



Hatch & Schultz, 1997

EURORDIS – consulting process in 2016

- Kathy Redmond

Redmond Consulting

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Build an identity which displays your values

courageous hard-working collaborative
solidarity respectful professional
vocal brave
credible Patients first unique
helpful authentic supportive innovative
determined legitimate optimistic
straightforward caring authoritative
informative visionary
agents of change

Values that guide EURORDIS in all that it does

As well as embracing the common European values of **democracy, mutual respect, solidarity, social justice** and **equality** EURORDIS is also guided by the following values:

- **Patients first** – EURORDIS puts patients first and endeavours to do what's right for patients and their families. In order to maintain its **legitimacy** in representing the needs, concerns and realities of its constituents EURORDIS stays independent from all other stakeholders with an interest in rare diseases.
- **Authentic** – EURORDIS is **credible** in representing the patient voice because its positions are based on contributions from its members and a wide range of PLWRD. EURORDIS ensures that its volunteers are people who understand what it is to be affected by a rare disease.
- **Authoritative** - EURORDIS strives for excellence in all that it does and to represent the patient perspective with the **professionalism** it deserves. EURORDIS believes in building its positions on the basis of available evidence drawn both from the scientific literature and the experiences of PLWRD.
- **Courageous** – EURORDIS has a strong sense of integrity and is **straightforward** in representing the needs, concerns and desires of PLWRD.
- **Collaborative** – EURORDIS recognises that common problems are often solved more effectively by finding synergies and promoting collective action. EURORDIS is **respectful** of the fact that many stakeholders can help improve the lives of PLWRD and therefore is open to collaboration with like-minded organisations that share its vision and goals.
- **Innovative** – EURORDIS is a **visionary** organisation that is highly entrepreneurial in seeking out and implementing new ways to serve PLWRD.

EURORDIS' distinctive characteristics

Patients first

- Independent
- Legitimate
- Holistic
- Humanistic
- Solidarity
- Balanced use of emotion
- Grass roots

Authentic

- Credible
- Trustworthy
- Genuine
- Representative
- «Finger on the pulse»

Professional

- Authoritative
- Well-informed
- Serious
- Evidence-based
- Intellectual
- Institutional
- Purist
- Reserved

Courageous

- Fortright
- Blunt
- Brave
- Relentless
- Persistent
- Consistent
- No «pussy footing»

Collaborative

- Respectful
- Collegiate
- Inclusive
- Non-competitive
- Consultative
- Pragmatic
- Modest
- Humble

Innovative

- Visionary
- Creative
- «Can-do» culture
- Open-minded
- Pioneering

Who are we?

Our vision

Better lives and cures for people living with a rare disease

Our mission

EURORDIS-Rare Diseases Europe works across borders and diseases to improve the lives of people living with a rare disease



Simple steps to achieve

- Email to members – send 3 adjectives to describe the organisation

- Define values

- Ask what they expect from an organisation?

Needs analysis

- Clearly communicate your vision – where you are going

Produce a vision and mission statement

- Slogan, vision statements, continually communicate them

Topics

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- Email responses and organisation
- Visual identity
- Social media



When answering emails – 5 elements



When answering emails – 5 elements



Timing – simple steps

- Answer calls and correspondence as quickly as possible
- Decide a « standard response time » which is acceptable per your schedule and workload
- Set an automatic response if over 48 hours

When answering emails – 5 elements



Show you listen

- First sentence should always acknowledge the sender
 - I understand you frustration
 - Thank you for contacting me
 - I am glad you shared with me
- Part of the email must be personalised
 - Repeat some of the words
- Show feelings, empathy

When answering emails – 5 elements



Thank you – simple steps

- Thank you
- Make the sender feel good about their contribution, no matter how small
- Explain how and what that person contributed to – be as concrete as possible
- Don't exaggerate, be authentic

When answering emails – 5 elements



Who's asking? – simple steps

- Stakeholder analysis
- Understand the person who is writing to you and why?
- EURORDIS example about answering emails for Rare Disease Day
 - Creating typical emails –ahead

When answering emails – 5 elements



Call to action – simple steps

- Close the email with a specific timing of when you are expecting the next contact
- Remind users of events coming up
- Website or newsletter links
- Give options about how to get involved

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Typefaces

MICROSOFT NEW TAI LUE BOLD

STRONG

Calibri
Clean

Sanvito Pro
compassion

Microsoft JhengHei UI Bold

Stability

Times New Roman

Tradition

Comic Sans MS
Friendly

Adobe Garamon
Reliable

Myriad Pro Italic
Modern

CANDARA BOLD
ADVOCATING

Colours

Youth

Orange

Optimism

Purple
Power

Importance

Boldness
Red

Blood

Calmness

Blue

Knowledge

Medicine

Formality

Black

Neutral

Positivity

Yellow

Clarity

Green

Nature



Examples



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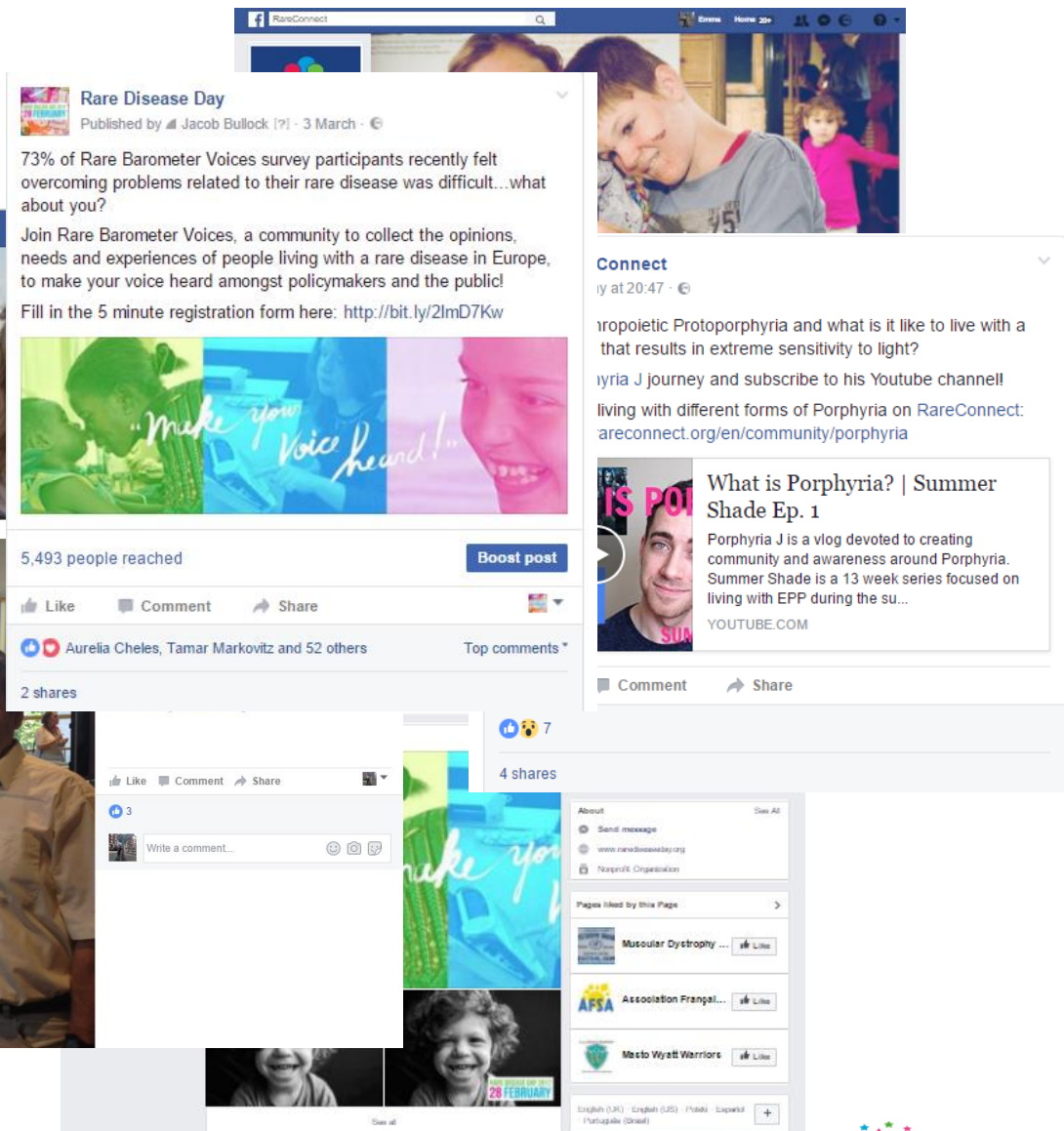
Social media campaign

- Free to sign up
- Create community
- Directly communicate to group which is interested – push communications

Dangers of social media

- Time consuming!
- Don't neglect it!
- Have a strategy for negative comments – don't engage in being defensive

Facebook



Twitter



Good morning to North, Central and South America! Have a fantastic day and remember



Following

#News at #EMM2017: Results from 1st European survey on the social impact of **#raredisease** are out now! **#RareBarometer** ow.ly/CPeM30bNTVp



3,000 rare disease patients & carers voice difficulties in balancing care & life

First Europe-wide survey on social impact of rare diseases publishes results

19 May 2017, Paris - The first Europe-wide [survey](#) on the social impact of rare diseases has revealed that rare diseases have a serious impact on everyday life for **over 80% of patients and families**.

Over 3,000 rare disease voices across Europe responded to the survey '*Juggling care and daily life: The balancing act of the rare disease community*', which was conducted via [Rare Barometer Voices](#) and in the scope of the EU-funded [INNOV4Care project](#), focused on promoting person-centred care for rare diseases.

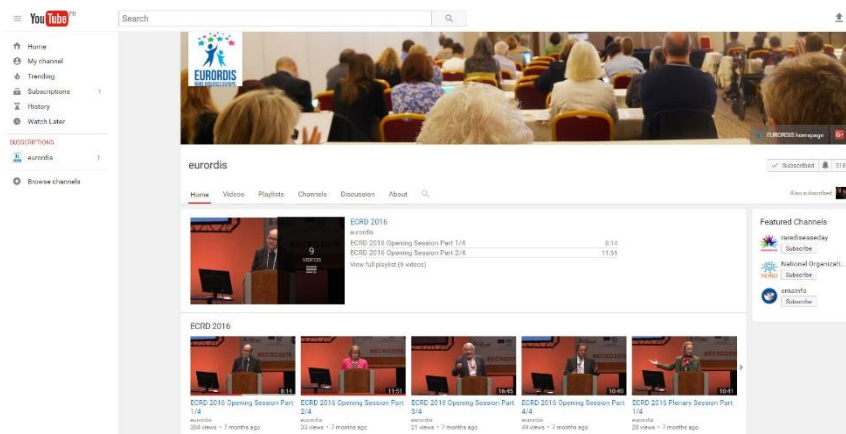
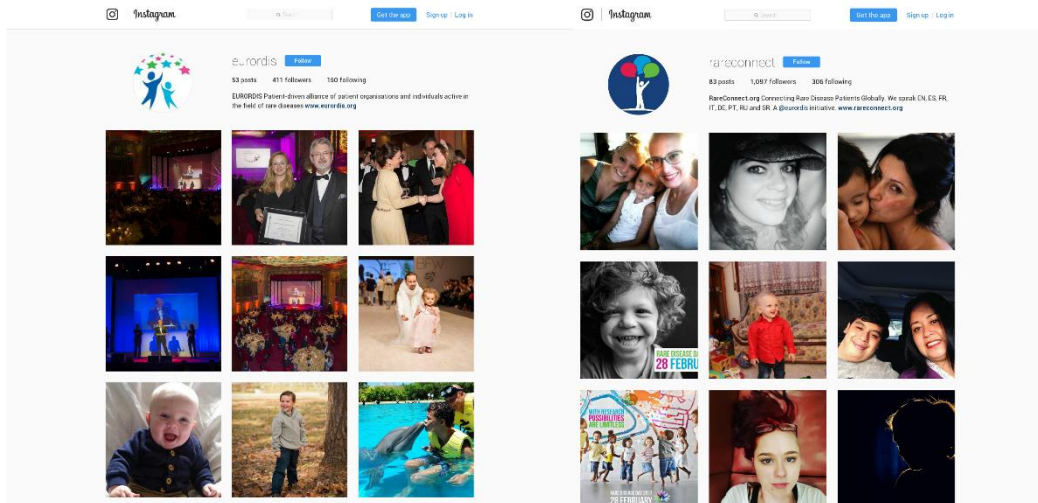
RETWEETS 3 LIKES 2

8:54 AM - 19 May 2017



A network of doctors tries to solve medical mysteries
The doctors and scientists in the Livingroom show how they work to solve
adventures in genetic science to identify rare diseases.

Other social media



Strategy for social media

- Consider facebook groups – feed themselves
- Only open an account at a time when you have the time to feed and answer comments



**Thank you for your
attention**

Lara Chappell

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