



# SMALL PATIENT ORGANISATIONS: COMMUNICATION

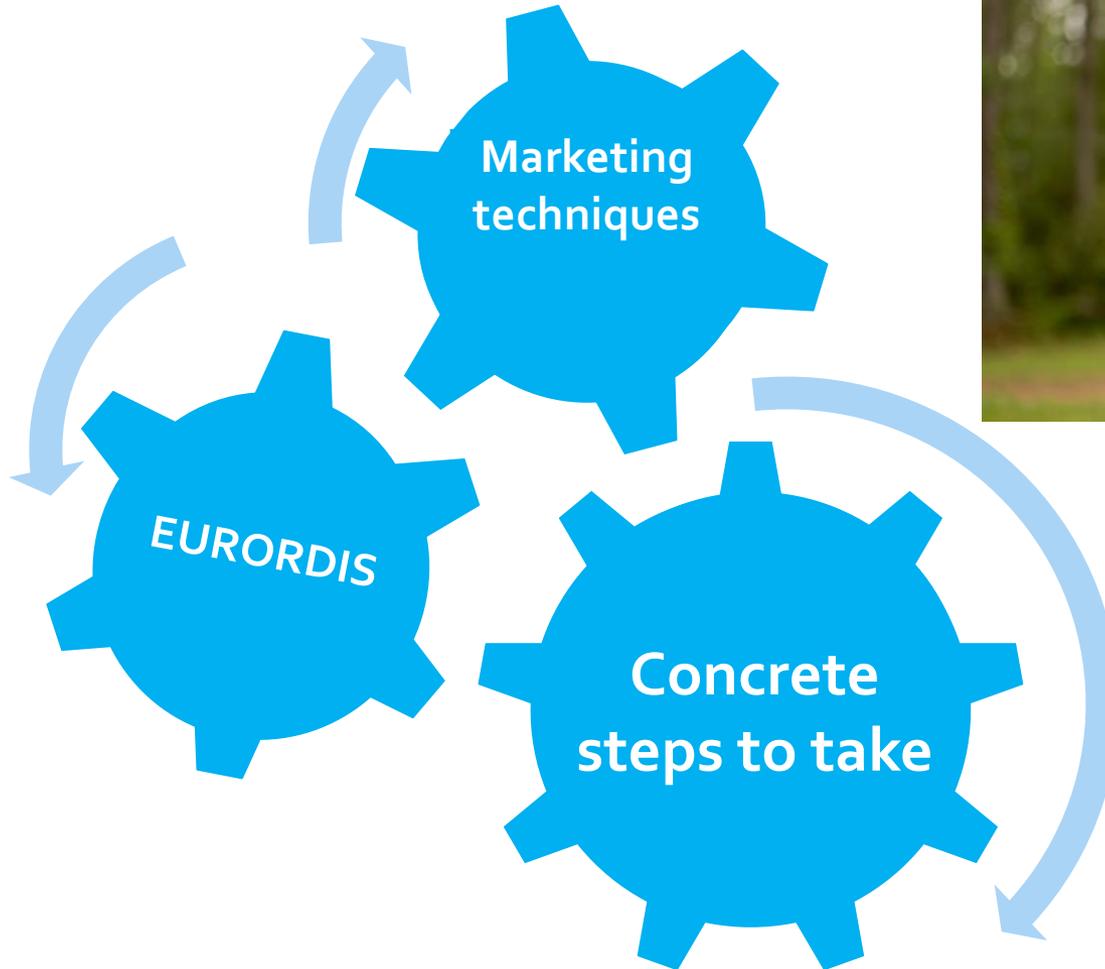
Creating a positive image and  
impact

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[EURORDIS.ORG](http://EURORDIS.ORG)



# Me, myself and I speaking today...



# Making a positive impact – simple steps!

- Low cost



- Little time



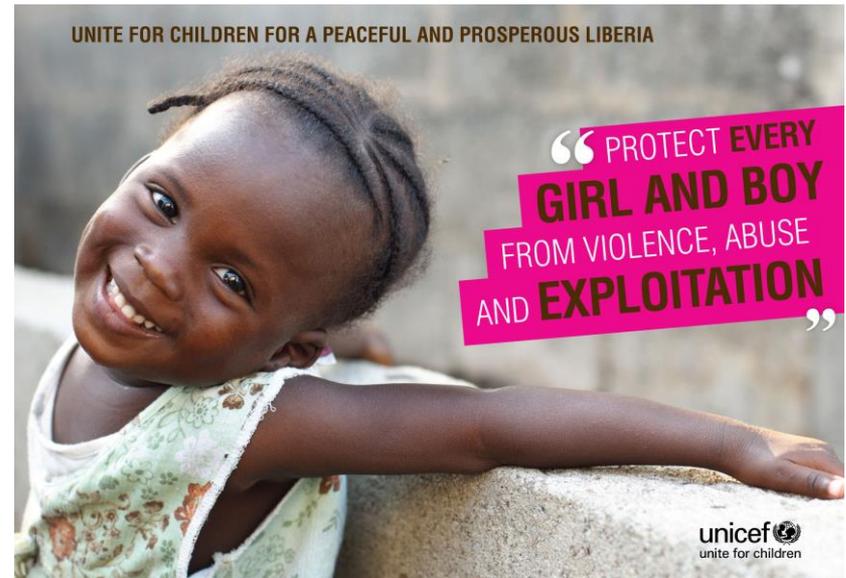
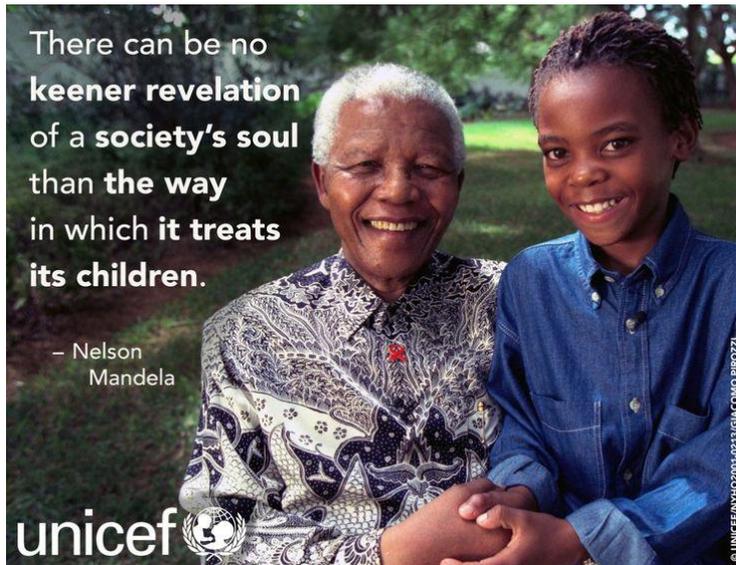
- Goal

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

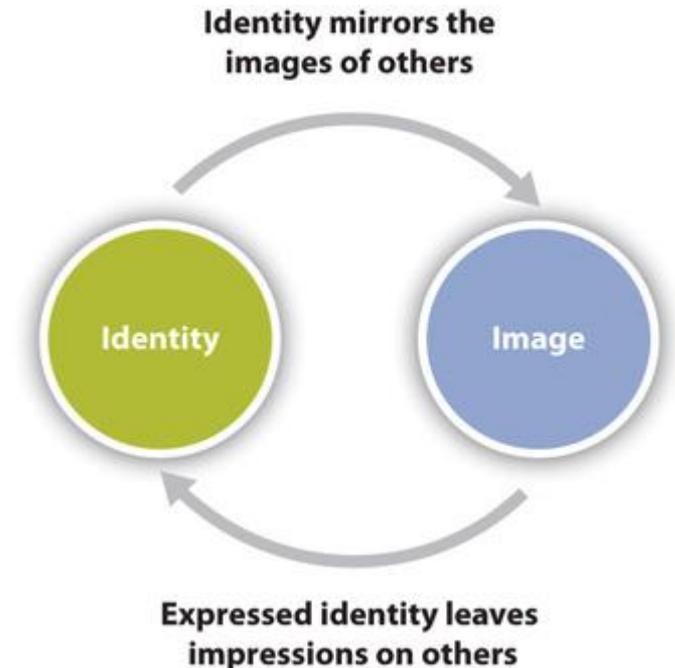


# Organisational identity

**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

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# Build an identity which displays your values

courageous  
solidarity  
hard-working  
collaborative  
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

- Forthright
- 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



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# 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

Importance

Blood

Red

Purple

Power

Boldness

Calmness

Blue

Knowledge

Medicine

Formality

Black

Neutral

Positivity

Yellow

Clarity

Green

Nature



# Examples



# Topics

- Organisational identity
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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



**Rare Disease Day**  
Published by Jacob Bullock [?] · 3 March ·

73% of Rare Barometer Voices survey participants recently felt overcoming problems related to their rare disease was difficult...what about you?

Join Rare Barometer Voices, a community to collect the opinions, needs and experiences of people living with a rare disease in Europe, to make your voice heard amongst policymakers and the public!

Fill in the 5 minute registration form here: <http://bit.ly/2ImD7Kw>

5,493 people reached

Like Comment Share

Aurelia Cheles, Tamar Markovitz and 52 others

2 shares

Write a comment...

4 shares

**Connect**  
y at 20:47 ·

ropoietic Protoporphria and what is it like to live with a that results in extreme sensitivity to light?

ryria J journey and subscribe to his Youtube channel!

living with different forms of Porphyria on RareConnect: [areconnect.org/en/community/porphyria](http://areconnect.org/en/community/porphyria)

**What is Porphyria? | Summer Shade Ep. 1**  
Porphyria J is a vlog devoted to creating community and awareness around Porphyria. Summer Shade is a 13 week series focused on living with EPP during the su...  
YOUTUBE.COM

Comment Share

Pages liked by this Page

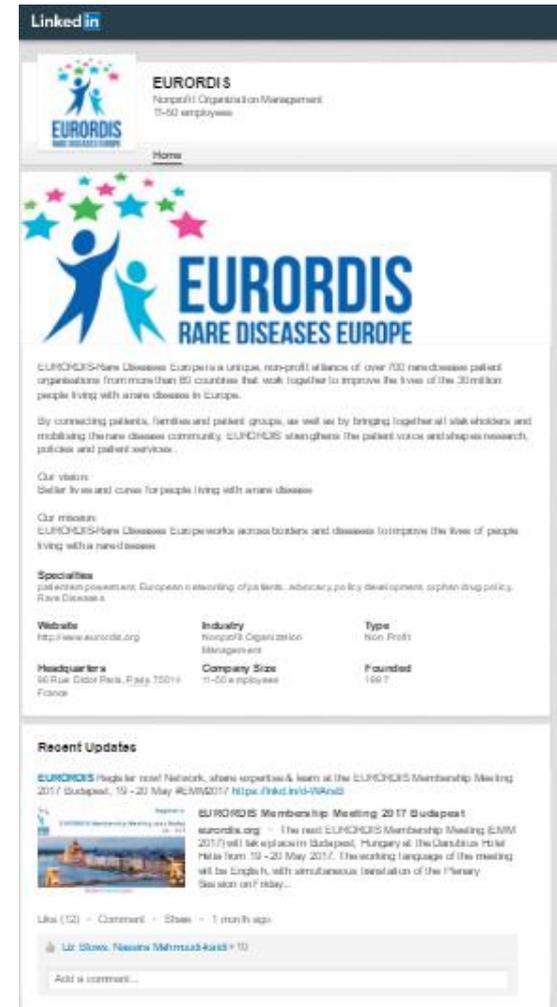
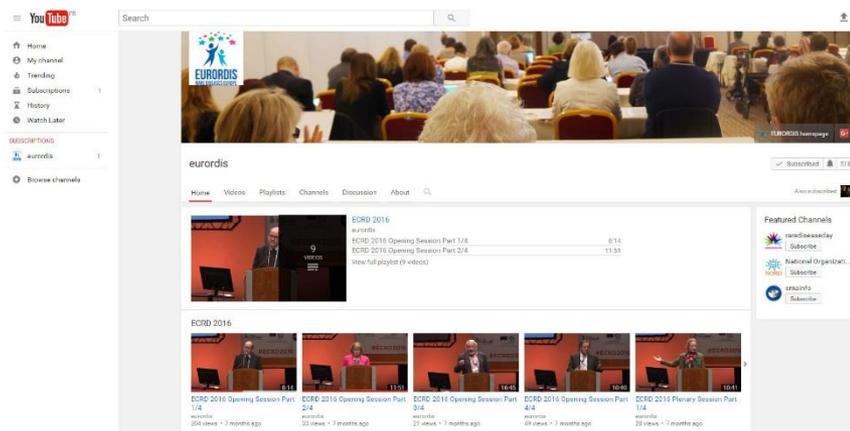
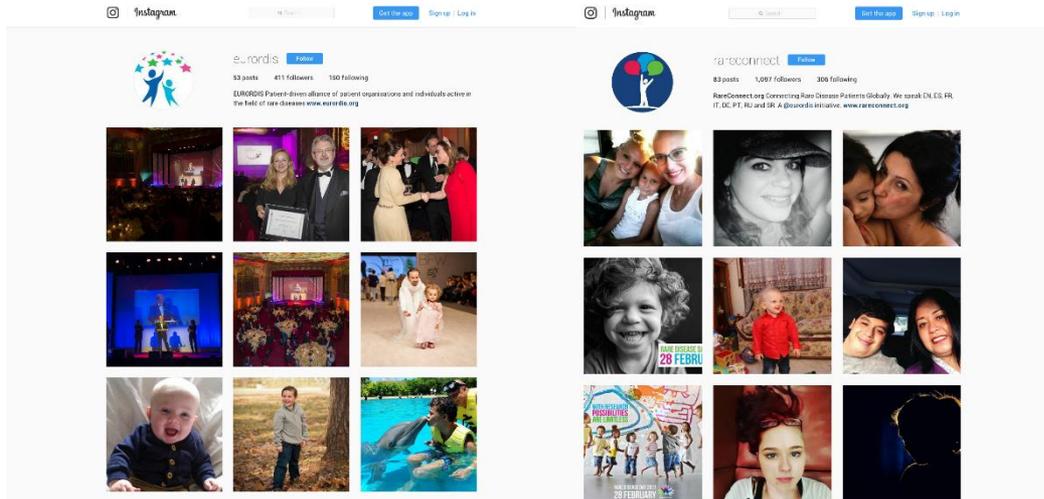
- Muscular Dystrophy ...
- AFSA Association Françal...
- Mesto Wyatt Warriors

English (UK) English (US) Hindi Español Portuguese (Brazil)

# Twitter




# 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**

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**EURORDIS.ORG**