SMALL PATIENT ORGANISATIONS: COMMUNICATION

Creating a positive image and impact

Lara Chappell, Communications Director, EURORDIS

EURORDIS.ORG
Me, myself and I speaking today...

Marketing techniques

EURORDIS

Concrete steps to take
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

There can be no keener revelation of a society’s soul than the way in which it treats its children.

– Nelson Mandela

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

• Organisational identity

• Email responses and organisation

• Visual identity

• Social media
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

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Build an identity which displays your values

courageous  hard-working  collaborative
solidarity  respectful  professional
vocal  brave  unique
credible  Patients first  innovative
helpful  supportive  authentic

determined  legitimate
straightforward  optimistic
informative

caring  authoritative

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.
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<thead>
<tr>
<th>EURORDIS’ distinctive characteristics</th>
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<td><em>Solidarity</em></td>
<td><em>«Finger on the pulse»</em></td>
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<td><em>Modest</em></td>
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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

• Organisational identity

• Email responses and organisation

• Visual identity

• Social media
When answering emails – 5 elements

- Timing
- Call to action
- Show you listen
- Who’s asking?
- Thank you
When answering emails – 5 elements

- Timing
- Call to action
- Show you listen
- Who’s asking?
- Thank you
Timing – simple steps

- Answer calls and correspondance 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

- Timing
- Show you listen
- Call to action
- Who’s asking?
- Thank you
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

- Timing
- Call to action
- Show you listen
- Who’s asking?
- Thank you
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 exagerate, be authentic
When answering emails – 5 elements

Timing

Call to action

Show you listen

Who’s asking?

Thank you
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

Timing

Show you listen

Thank you

Who’s asking?

Call to action
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
Topics

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Typefaces

MICROSOFT NEW TAI LUE BOLD

STRONG

Calibri
Clean

Times New Roman
Tradition

Myriad Pro Italic
Modern

Microsoft JhengHei UI Bold

Stability

Comic Sans MS
Friendly

Adobe Garamon
Reliable

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
Topics

• Organisational identity

• Email responses and organisation

• Visual identity

• Social media
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

The Voice of Rare Disease Patients in Europe

Rare Disease Day
Published by Jacob Bellock | Fri 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!


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 summer.

YOUTUBE.COM

5,493 people reached

5 likes

2 shares

4 shares

Comment

Share
An estimated 5000 have been identified approximately 6 to
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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