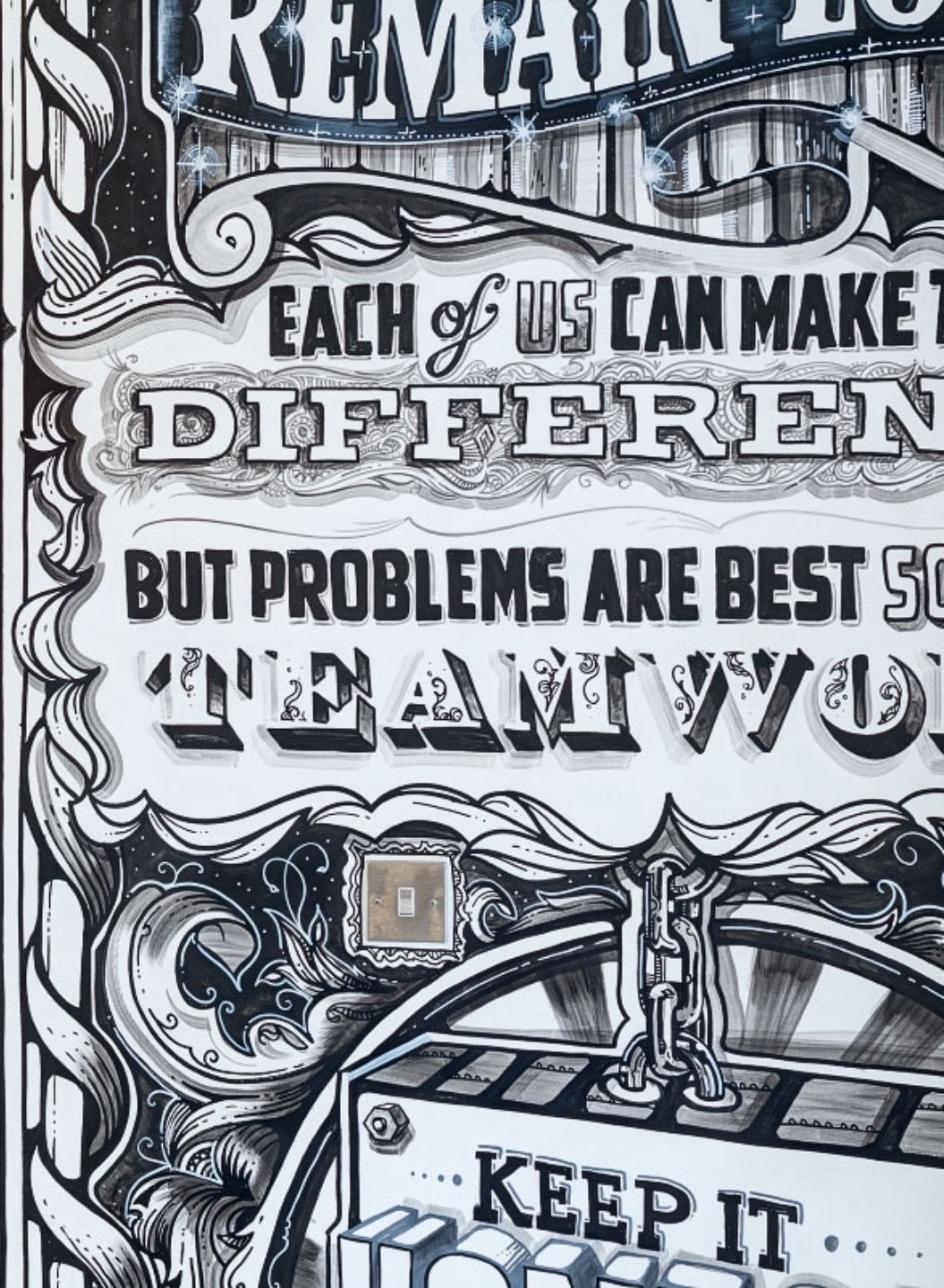


Today's Media Landscape & Tools to Get Started.

December 9, 2020

runder•finn



The media can help you spread the word about Rare Disease Day 2021

Raise awareness and tell your unique stories

Encourage people and organizations to support the cause and take action

Reach and engage a larger audience in your country or region





But COVID-19 has put journalists under pressure...

Redundancies mean smaller teams with more news to cover

Many face reduced working days and hours

Deadlines are tight!

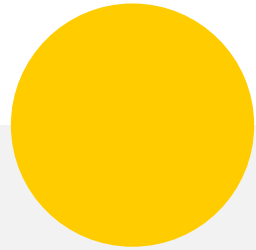
Pandemic developments create competition for health stories

What are journalists looking for today?



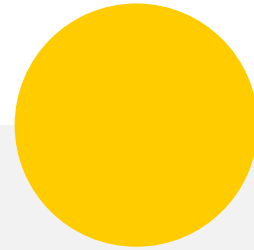
SIMPLE STORIES

A short, focused email “pitch” with a clear call to action



HUMAN FOCUS

Real-life and expert perspectives to bring your story to life and show why it matters



VISUALS

High quality photography, graphics or videos to make an impact and cut through the noise



LOCAL ANGLE

Important statistics and facts relevant to your country or region

How to get started. Understanding the...



WHAT

WHO

HOW



WHAT is your story?

What are the “key messages” you want people to know

- Why is your story important?
- What challenge do you want to overcome?
- What evidence do you have?

Is there an action you want people to take

- Visit a website?
- Sign a pledge?
- Show support?
- Attend a virtual event?

Who can help you tell the story

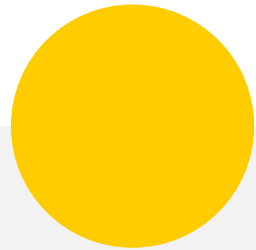
- Individuals or families living with rare disease
- Healthcare professionals
- Patient group representatives

Questions to ask yourself when thinking about your story



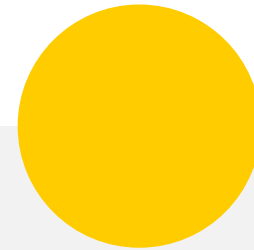
SIMPLE STORIES

How would you explain rare diseases in an easy-to-understand way?
How can you show the impact of rare diseases?



HUMAN FOCUS

Do you have a compelling patient story you can tell?
Do you have a doctor who can serve as an expert?



VISUALS

Do you have videos of patients?
Do you have photos from events?



LOCAL ANGLE

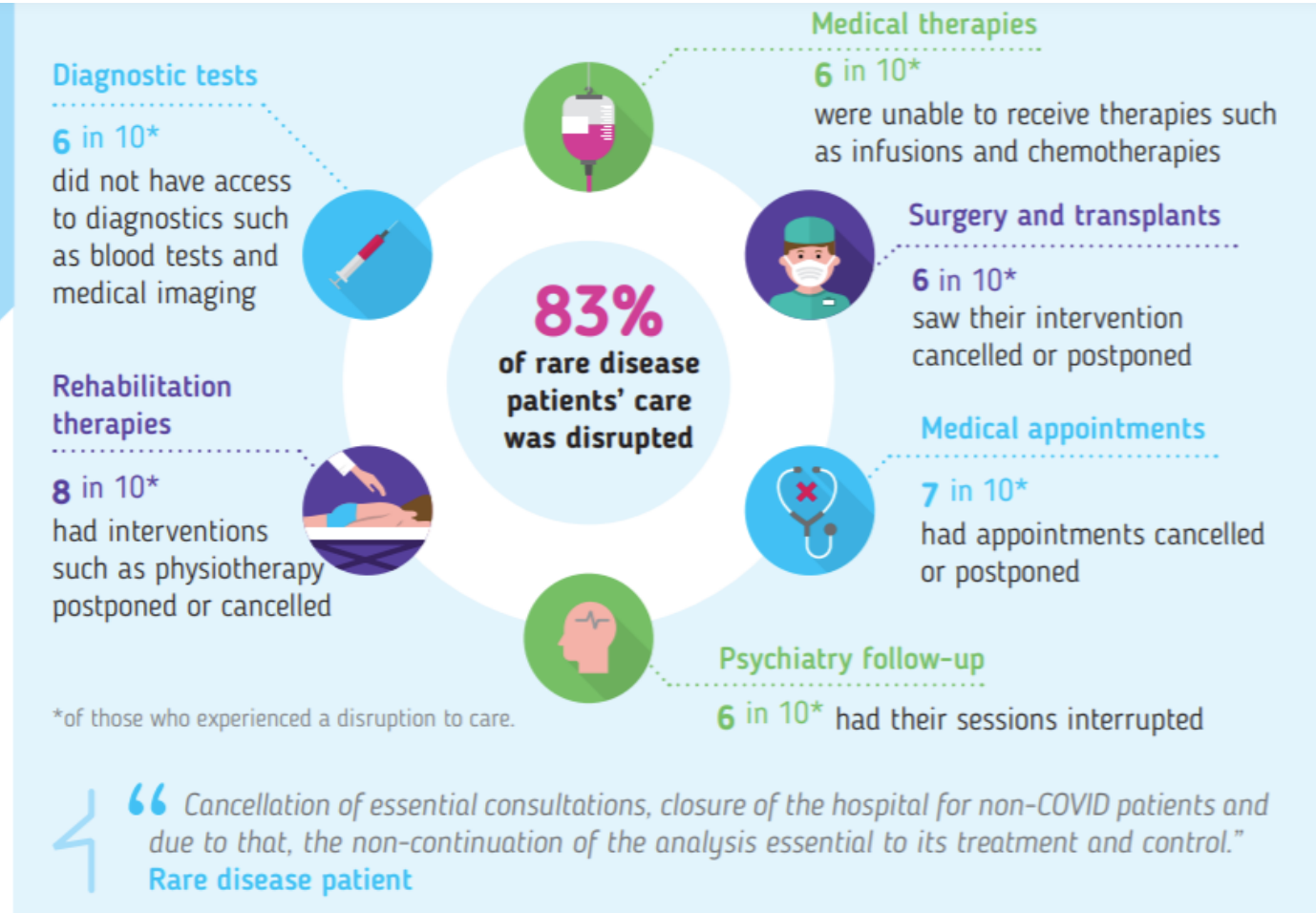
Can you hold a local virtual event?
Do you have any local statistics about rare disease prevalence/
COVID-19 impact?

Leveraging statistics from the Rare Disease Patient Barometer

COVID-19 caused a **severe disruption to care** for people living with a rare disease

HOW HAS COVID-19 IMPACTED PEOPLE WITH RARE DISEASES?

November 2020



Source: http://download2.eurordis.org/rbv/covid19survey/covid_infographics_final.pdf



WHO should you reach out to?

Define what type(s) of media you'd like to engage with, which could include:

- Print
- Online
- Broadcast TV
- Radio

Consider who is most likely to cover the story

Develop your media list with the following information

- Journalist name
- Contact information (email, telephone number)
- Recent articles/coverage



HOW to reach out?

1. Make your subject line catchy

- Example: "STUDY RESULTS: 83% of rare disease patients' care disrupted due to COVID-19"

2. Don't bury the lead

- Give the **Who**, **What**, **When**, **Where**, **Why**
- Don't be afraid to **bold**, underline, and *italicize* key words

3. Personalize the pitch

- Have you worked with this person before? Remind them!
- If you don't know them, look them up on LinkedIn/Twitter (e.g., do they go by Matt or Matthew?)
- What have they written about recently? Mention the article!

4. Simplify the pitch

- Write a short and simple email pitch summarizing your story

5. Pitch at the right time

- It's best to reach out early in the morning (8 – 9 AM)

6. Follow up, follow up, follow up

7. Respond quickly

8. Prepare for the interview

In summary...

WHAT

Define your
unique story

WHO

Develop
tailored list of
media targets

HOW

Simplify and
follow-up

Thank you!