



**NORD**<sup>®</sup>  
National Organization  
for Rare Disorders

# Crisis Communications

*COVID-19 Rapid Response Leadership Series Webinar*

Alone we are **rare**. Together we are strong.<sup>®</sup>



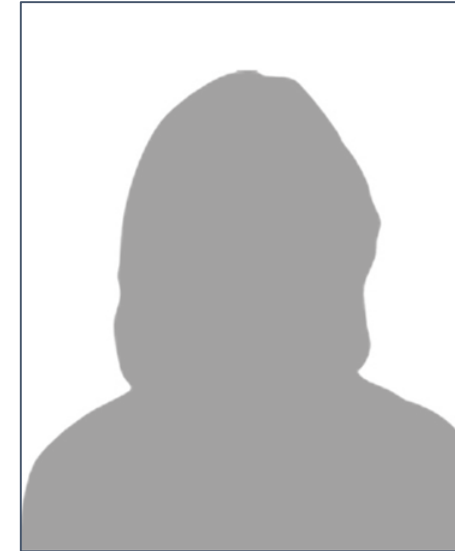
# Your NORD Membership Team



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[rarediseases.org](http://rarediseases.org)

### **ABOUT THE COVID-19 RAPID RESPONSE LEADERSHIP SERIES**

NORD has developed a multi-faceted program to support patient organizations through education, training and resources to better equip them to face the additional challenges brought on by this pandemic. Topics covered in this program are informed by NORD's expertise in capacity-building and nonprofit management during crisis, input from member organizations in NORD's closed Facebook group, and direct outreach. A critical component to this program is the timely cultivation and delivery of these resources to ensure rare disease organizations remain solvent in this time of crisis.

### **PROGRAM SPONSORSHIP**

This fund is made possible by individual donations, grants and corporate sponsorships.

**SANOFI GENZYME** 



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# Agenda

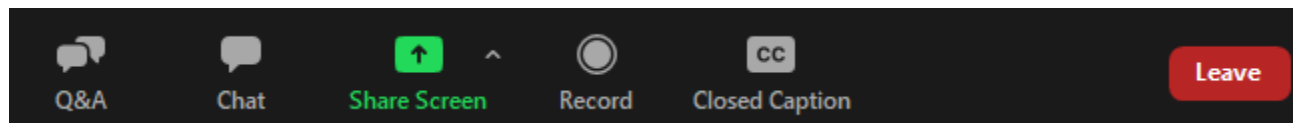
## Opening

*Debbie Drell, NORD Director of Membership*

## Keynote Presentation

*Michael Williams, Board Veritas Media Relations & Journalism Senior Consultant*

## Q&A





**NORD**, an independent nonprofit, is leading the fight to improve the lives of **rare disease patients and families**.

We do this by supporting patients and organizations, accelerating research, providing education, disseminating information and driving public policy.



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# Crisis Communications



Michael Williams  
Board Veritas Media Relations &  
Journalism Senior Consultant

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# Learning Objectives

- Understand the basics of crisis communications through practical examples (the good, the bad, the ugly).
- Learn what it means to triage a crisis.
- Recognize the three pillars of crisis communications and why they are integral to successfully navigating through a crisis.
- Hear how a crisis can be an opportunity to meet fiscal challenges and become a trusted source of information.
- Gain strategies on engaging your Board of Directors, including determining who should comment and who shouldn't.

# Crisis Communications 101

- Practical examples of Crisis Comms 101:  
The Good the Bad and the Ugly
- What is a Crisis
  - What does it look like?
  - Who defines crisis status for the organization?
- What is at stake?





# Case Study #1: Wounded Warriors



## The Cost

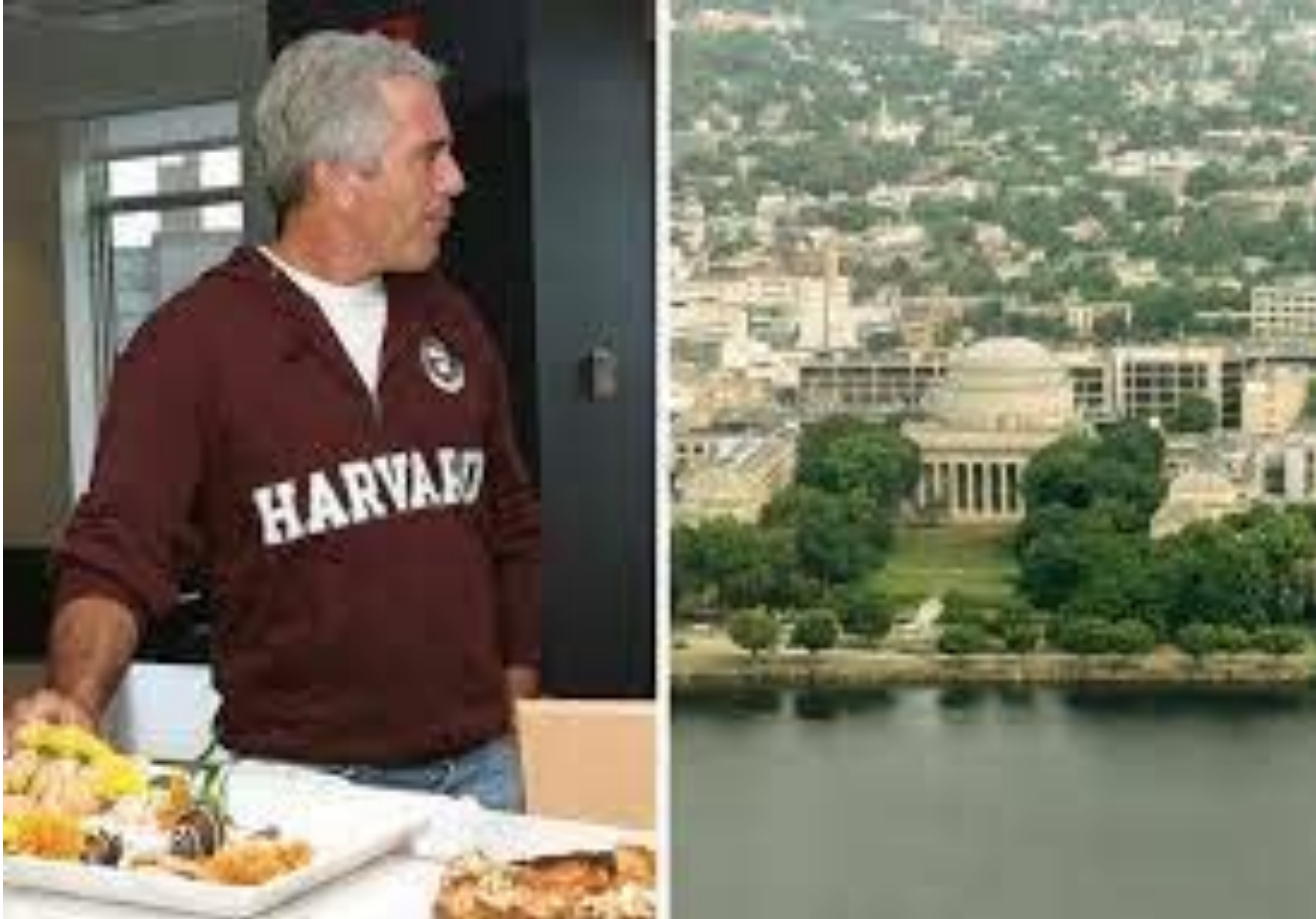
- Millions in revenue
- Federal scrutiny
- Reputation

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# Case Study #2: MIT Media Lab and Jeffery Epstein



## The Cost

- Key staff
- Revenue from donors
- Reputation

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# Case Study #3: Tylenol

## THE DAILY HERALD

Arington Heights Edition

110th Year - 35¢ - Paddock Publications

Friday, October 1, 1982

6 Sections - 25 Cents

### 5 dead after taking Tylenol capsules filled with cyanide

By Peter Naiman and John Van Wye

Five children died as a result of an alarming episode of Tylenol capsules filled with cyanide.

The poison triggered a panic that swept the area, prompting police and state police to search for and seize Tylenol capsules in stores, homes and hospitals. The search for a killer continued for days as the police hunted for the capsules. The capsules were found in a store in Chicago, and the police searched for days to find the killer.

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TWO BROTHERS, Stanley and Adam Janus, died of the toxin, 1025 S. Mitchell St., Arlington Heights, after ingesting lethal capsules. Stanley's mother, wife and brother survived.



10-YEAR-OLD Mary Kalkman, left, died after taking a Tylenol capsule like the one above. Deadly capsules were purchased at five local food stores, shown on the map.

### The Cost... and the benefit

- Even though police were convinced that the incident was confined to the Chicago area. The CEO of Johnson & Johnson [ordered the company](#) to pull their product off all US shelves (more than 31 million containers).
- Johnson & Johnson's forthright response (and spending \$100 million on tamper-proof packaging) helped convince the public the product was safe.
- Tylenol regained its #1 market position within a year.
- In terms of how a corporation should behave in times of crisis, the gold standard is still Tylenol.

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# Defining a Crisis



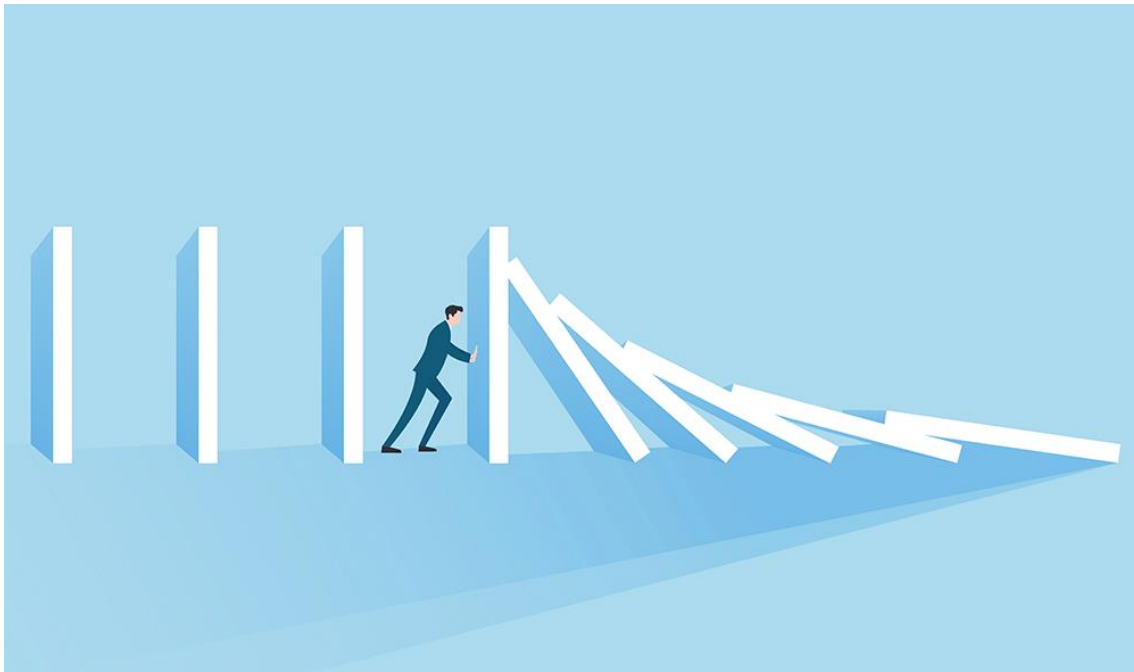
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# What is a “Crisis”?

- Company **financial woes**, such as layoffs and bankruptcy
- **Employee wrongdoing**, such as sexual harassment claims
- **Natural disasters**, such as floods, fires and hurricanes
- Forced closures due to an **owner’s illness or death**
- **Cybersecurity issues**, such as stolen data and a cyber breach
- **Community dissatisfaction**, such as protests
- **Reputation issues**, such as rumors, scandals, and threats
- **COVID-19 specific issues**
  - Delayed clinical trials
  - Cancelled fundraising event

# The 3 Pillars of Crisis Communications



- Honesty
- Transparency
- Frequency

# Who Leads in a Crisis?

“Them that know won’t say.  
Them that will say, don’t know.”

1. Information gatherers
2. Message crafters
3. Information disseminators



# 9 Steps of Basic Crisis Management



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*Stacy McCaroll and daughter, Cystic Fibrosis*



# Steps 1 - 2 - 3

## 1. Recognize the forming crisis and get ready for action

- Grab that Crisis Comms Playbook
- Gather any and all available information, both internally and externally

## 2. Alert the team and provide information

- Make sure the chain of command and communication is clear
- Decide if your team needs to pause any scheduled social media posts, client emails, content, etc.

## 3. Develop your messaging

- Know the relevant internal, leadership, customer, and media talking points
- Establish a spokesperson and a source of truth where you can direct traffic to (e.g., a blog post)

# Steps 4 - 5 - 6

## **4. Prepare your deliverables (as necessary)**

- Prepare a press release
- Prepare social media posts
- Prepare for a press conference

## **5. Review with your legal team/stakeholders**

- Report relevant information to executives and decision makers
- Consult with legal team/executives before sending out any external communications

## **6. Deliver the deliverables**

- Send out press releases and social media posts (if applicable)
- Ensure your spokesperson has a clear voice throughout your deliverables

# Steps 7- 8- 9

## 7. Monitor for additional coverage and responses

- Look closely at the social conversation
- Check for spikes in media coverage
- Respond when and where appropriate

## 8. Reassess the situation

- If the crisis is contained, breathe a sigh of relief
- If not, consider reaching out to some journalists and/or influencers- who are advocates of your brand- to help mitigate the crisis

## 9. Perform a postmortem

- Analyze where you handled the crisis effectively and where there was room for improvement
- Update your crisis comms plan for future events

# Crisis as Opportunity

- Meeting fiscal challenges
- Becoming a trusted source of information
- The Mother of Invention





# Questions?



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# NORD COVID-19 Rapid Response Leadership Series



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*Vaughn family: Son, Morgan (left), diagnosed with Necrotizing Enterocolitis at four days old*

# NORD's COVID-19 Rapid Response Leadership Series

## NORD® COVID-19 RAPID RESPONSE LEADERSHIP SERIES

### Tentative Rapid Response Video Topics:

- ✓ Transitioning to Virtual Events: Considerations from NORD
- ✓ Fundraising in a Pandemic – June 4
- ✓ Crisis Communications: COVID-19 and the Future – June 25
- ✓ Leader Roundtable: Virtual Platforms for Engagement – June 29
- ✓ Building a Village: How to Re-Engage Your Board Members, Leaders and Volunteers – July 8







Thank you.



Alone we are rare. Together we are strong.®

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