

What is a press release?

A press release is a prewritten summary about an event or activity that a group of people are holding. They inform the public of issues going on in their communities and how to get involved.

What is the goal of a press release?

The goal of a press release is to be clear, concise, and engaging so that the general public are interested in attending or supporting an event. Furthermore, with your press release, it should be very clear that you are bringing awareness to rare diseases or a specific disease affecting people in your area.

How to write a press release:

Having trouble getting started? Here are a few things to keep in mind to make the job easier.

- The five W's and one H are what you should really focus on answering first:
 - What am I talking about?

Rare Disease Day is an annual awareness event that takes place on the last day of February every year. This year the XYZ Group will be hosting an event to raise awareness about XYZ Disease.

• Who is this about?

XYZ Disease affects less than 200,000 people in the US alone – classifying it as a rare disease! One patient, Jane Doe, age 50, is currently living with XYZ Disease and helping spread awareness. (In this part, share 3-5 sentences about that patient that will draw the public in and help put a face to the organization. Talk about their journey, the disease, or what their ambitions or future may look like.)

• Why are we holding an event/why does this cause matter?

Since rare diseases are, well, rare we are holding the FUNdraiser to raise awareness and have fun doing so. Because XYZ is fairly new, we hope that by holding the event we may draw funds to help research that could lead to treatment or even one day – a cure!

- Where will the activities be held? Our XYZ FUNdraiser will be held at 1 Main Street, Hometown, State.
- When will the activities be held?

The FUN will begin around 11:00 in the morning and go on until 5:00.

• How can other people get involved?

If you'd like to participate in the event, the XYZ Group would love to have you come out – friends and family included. If you'd like to volunteer your time or for more information about XYZ Disease or future projects please contact John Doe at <u>email@email.com</u> or at our phone number (123)456-7890.

If you answer these questions, the majority of your press release will be written for you!

- The next thing you should consider is formatting.
 - Give the press release a headline that will grab reader's in
 - Headlines should give a quick summary of the piece
 - Headlines should be clear
 - Headlines should be bolded and centered before your press release's body copy
 - Press releases are short and concise like news stories.
 - Paragraphs should be short and to the point
 - Maximum page length should be two pages
 - Double-check punctuation, grammar, spelling, and page formatting before sending out press releases to reporters or editors.
 - When using acronyms, first spell out the full title of thing being abbreviated.
 - Once the full title is abbreviated, put in parentheses the acronym you will be using through the rest of the release.

Xenon Yellow Zebra Group (XYZ Group)

A sample press release:



Rare Disease Day[®]

FOR IMMEDIATE RELEASE

A FUNdraiser by the XYZ Group hopes to spread awareness on Rare Disease Day

HOMETOWN, STATE – February 2X, 20XX – Rare Disease Day is an annual awareness event that takes place on the last day of February every year. This year the Xenon Yellow Zebra Group (XYZ Group) will be hosting an event to raise awareness about Xenon Yellow Zebra (XYZ) Disease.

XYZ Disease affects less than 200,000 people in the US alone – classifying it as a rare disease! One patient, Jane Doe, age 50, is currently living with XYZ Disease and helping spread awareness. (In this part, share 3-5 sentences about that patient's personal story that will draw the public in and help put a face to the organization. Talk about their journey, the disease, if it runs in the family, how they were diagnosed, what their ambitions or future may look like, or anything else that makes their story unique.)

Since rare diseases are, well, rare we are holding a FUNdraiser to raise awareness and have fun doing so. Because XYZ is fairly new, we hope that by holding the event we may draw funds to help research that could lead to treatment or even one day – a cure!

Our XYZ FUNdraiser will be held at 1 Main Street, Hometown, State. The FUN will begin around 11:00 in the morning and go on until 5:00.

If you'd like to participate in the event, the XYZ Group would love to have you come out – friends and family included!

If you'd like to volunteer your time or for more information about XYZ Disease or future projects please contact John Doe at <u>email@email.com</u> or at our phone number (123)456-7890.

For more information about Rare Disease Day, visit <u>http://rarediseaseday.us/</u>. To search for information about rare diseases, visit NORD's website, <u>www.rarediseases.org</u>. To learn more about rare diseases, visit NORD's website, <u>www.rarediseases.org</u>.

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Media contacts:

[If applicable, insert your organization's media officer with contact information]

Jennifer Huron, NORD, 203-744-0100, jhuron@rarediseases.org