

#EQUIDAD #SALUD #EDUCACIÓN #DIGNIDAD  
#TRABAJO #JUSTICIA #INCLUSIÓN

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**¡MOSTRÁ TUS RAYAS!**



CADA RAYA DE LAS CEBRAS ES ÚNICA.  
LAS ENFERMEDADES POCO FRECUENTES TAMBIÉN.  
DETRAS DE CADA RAYA, HAY UNA HISTORIA DE VIDA.

RARE DISEASE DAY®



CON EL APOYO DEL  
DEFENSOR DEL PUEBLO DE LA NACIÓN

**FADEPOF**  
Federación Argentina  
de Enfermedades Poco Frecuentes



## “How to effectively approach media to boost your Rare Disease Day ”

**EURORDIS**

**Argentina- 09 Diciembre 2020**

**Roberta Anido - Presidente**

**Federación Argentina de Enfermedades Poco Frecuentes (FADEPOF)**

Email: [presidente@fadepof.org.ar](mailto:presidente@fadepof.org.ar)

[www.fadepof.org.ar](http://www.fadepof.org.ar)



The **Argentine Federation for Rare Diseases (FADEPOF)** It's a non profit civil society, second degree, formed and led by the community of patients and or family members.



**FADEPOF** emerged as workspace in June 2011 and was formally established in **December 2013**. It currently has a membership of **76 members** between organizations and groups of patients and groups of patients /relatives of different rare diseases.



Works at the **local, provincial and national level**. Also in **regional and global alliances** representing and supporting the communities of people with rare diseases and their family and social environment.

FADEPOF ES  
MIEMBRO DE:



**RARE DISEASES INTERNATIONAL**  
A EURORDIS INITIATIVE



**csem**  
Civil Society Engagement Mechanism for UHC2030



**Red APTA**  
Red Argentina de Pacientes para Terapias Avanzadas



# ABOUT RARE DISEASE IN ARGENTINA

In Argentina it is estimated that there are 3.5 million people affected with any of the 8 thousand rare diseases.



Affect less than  
Populations (LAW 26.689)  
**1 in 2.000**



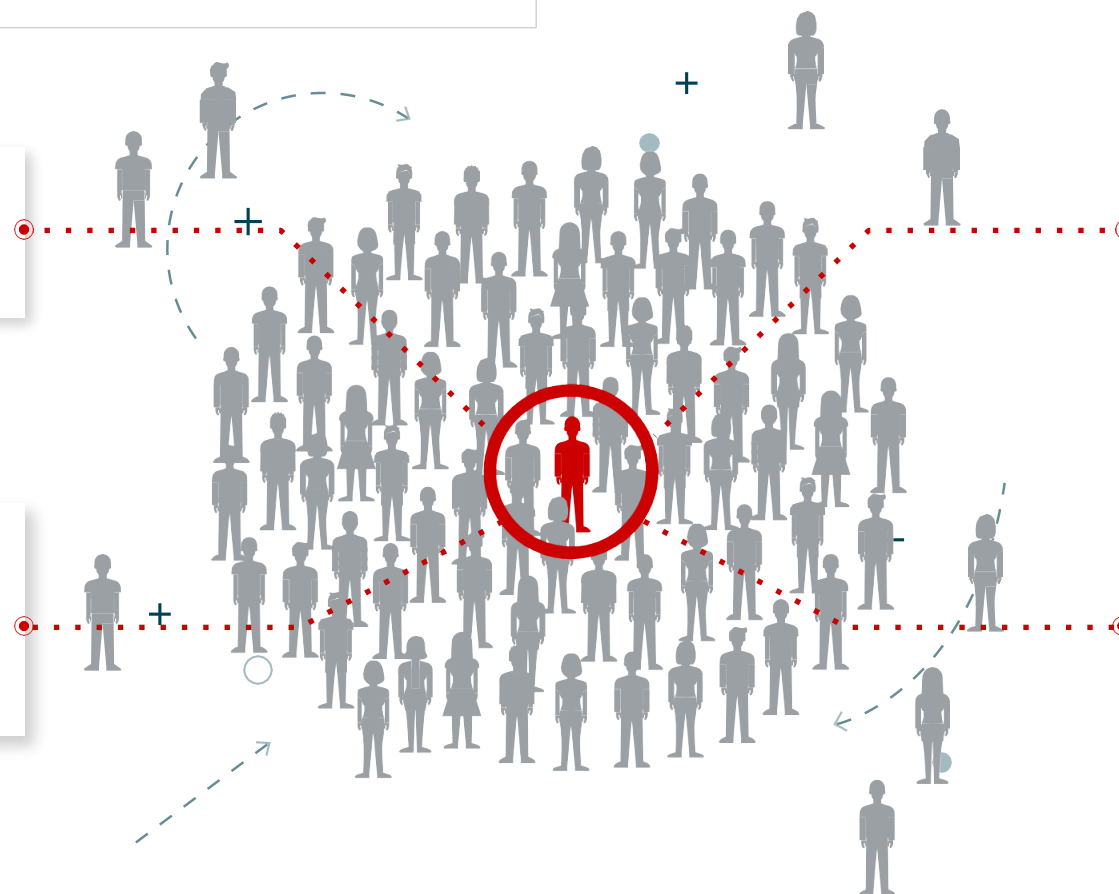
Are aprox. **8.000 RDs**  
identified by the **WHO**  
Of great etiological  
diversity between each  
one.



Present great **etiological, diagnostic and prognostic** complexity.



Wide diversity in the **demographic distribution** of affected people and **specialized health professionals..**





# GOOD PRACTICES IN SPREADING MASS CAMPAIGNS



**Identify the message to convey** – MOTTO



**Have a creative idea**– Meaningful message with a call to action for the community in general (simple to do it)



**Have human & financial resources for its realization.** (volunteers, CSR, agreements, etc.)



**Identify the most succesful communication channels** (social networks, only FB)



**Having a specialized agency will provide more changes of achieving it.** (experience of working agreement with Ketchum Agency)







# GOOD PRACTICES IN SPREADING MASS CAMPAIGNS



**Key Visual** – FADEPOF 2020 Campaign

**Image Description:** Cut profile of a zebra. Phrases and international logo of the RARE DISEASE DAY

**Motto:** ¡Show your stripes. Each stripe of zebras are unique. Rare Diseases too!.. Behind each stripe there is a life story.  
**As not to leave no one behind**  
February 29,2020

## Campaign 2020

### Objectives:

- Increase the recognition of RD and their visibility in social health systems so that they are considered in the formulation and implementation of municipal, provincial and national public – policies.
- Promote equity in the enjoyment of the rights of people with RD, so as not to leave no one behind.

**Motto:** ¡SHOW YOUR STRIPES!

### Rational:

- Not always when hoofs are heard, they will be horses, they also be zebras.
- Usually the RDs are zebras of unique stripes still relegated from socio-sanitary policies.
- It is necessary to "SHOW" the stripes of people with RD, as not leave no one behind in equal rights such as health, education, work, justice, inclusion and dignity!



The 2020 campaign was aligned with the international initiatives of RDI , Eurordis & NORD. And in correlation to the political declaration adopted during the high-level meeting on UHC at the headquarters of the UN in New York in the framework of the general debate of the general assembly of Sept 23, 2019 and the report E/2019/52 office of the United Nations high commissioners for human rights.



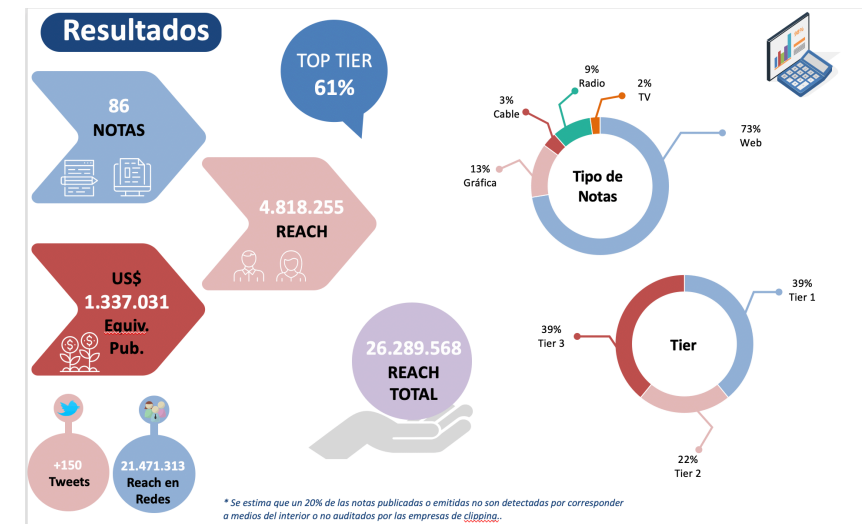
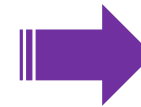
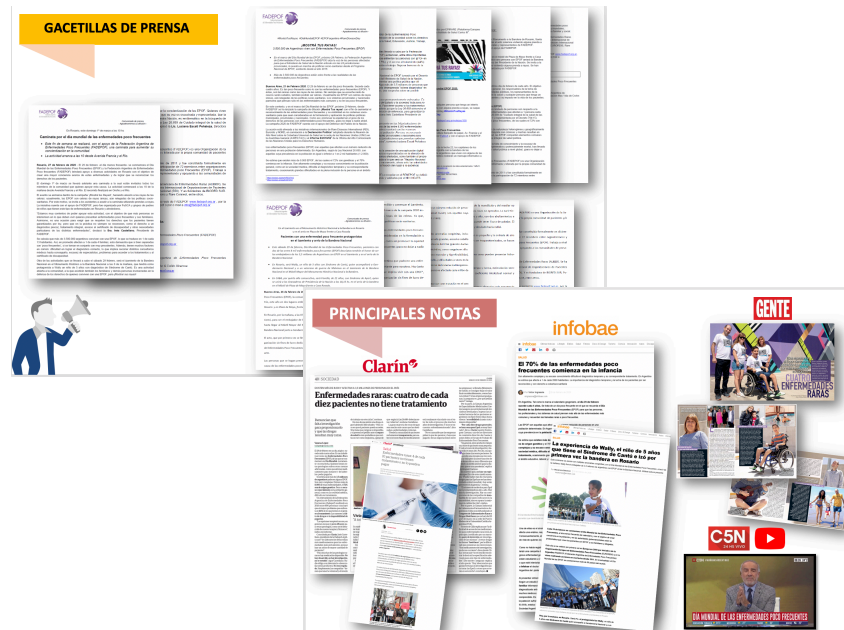


# GOOD PRACTICES IN SPREADING MASS CAMPAIGNS

**FADEPOF**  
Federación Argentina  
de Enfermedades Poco Frecuentes



**Press action (with national media) carried out by specialized agency in health communication (specific agreement)**



**Major agency support at the national level. Ex. Ombudsman of the Nation as supporting the message & rights.**





# GOOD PRACTICES IN SPREADING MASS CAMPAIGNS

Others actions of spreading mass campaigns :



**Raising the Flag at the National Monument of the Argentine Flag. (1st Year)**

**Raising the Flag in front of the Government House. (5th consecutive year)**



**Superl League** (main football matches of the 1st division. ( 2nd consecutive year)



**Support individual “good” actions of member organizations. ( helping their action aligned with FADEPOF proposal)**

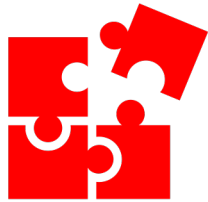


**Key:** Look for actions that have the greatest impact possible at the lowest price.





# GOOD PRACTICES IN SPREADING MASS CAMPAIGNS



## Proposal experience with CAEME

- Action unlinked to our own campaign.
- Relationship evaluation.
- High human and financial resources for a single medium impact action.
- Did not include sponsorship for other own actions of campaign.

**Outcome/ decision ➡ The proposal was not accepted**







THANKS!!



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DISEASES  
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