

YOUNG PEOPLE WITH RARE DISEASES

THE VALUE OF FACING LIFE



Co-funded by the
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of the European Union



Federación
asem



OBJECTIVES

The aim of this initiative, co-funded by the Erasmus+ Programme of the European Union is to give visibility to those young people who suffer from rare diseases, not only as a mechanism to recognize their value, but as an example of good practices of which other young people in their situation can learn to live with their disease and reach the highest levels of inclusion.



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CMTFrance

Ü
UNIAMO

**Duchenne
Parent
Project**



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PARTNERSHIP

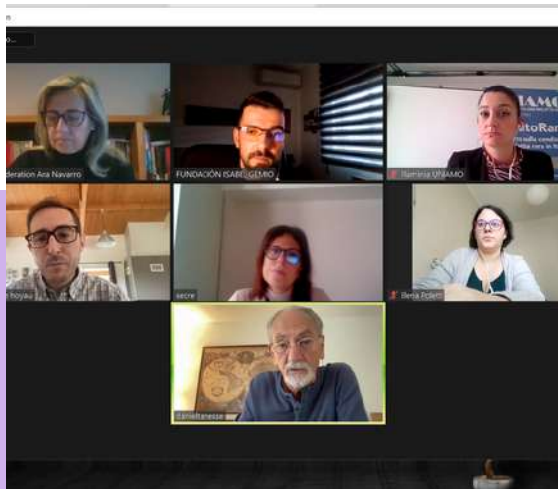
- Fundación Isabel Gemio (Spain for the Research of Muscular Dystrophies and other Rare Diseases, was born in 2008 with the aim of contributing to accelerate research in those biological, genetic or therapeutic aspects that can influence the development and application of curative treatments to those affected
- Federación Española de Enfermedades Neuromusculares (ASEM) (Spain), a non-governmental organization that brings together associations and foundations for neuromuscular diseases. It currently represents more than 60,000 people affected throughout Spain.
- Charcot-Marie-Tooth et Neuropathies Peripheriques (France), an association of patients with peripheral neuropathies, which aims to break the isolation by bringing together people with CMT or similar neuropathies.
- Uniamo Federazione Italiana Malattie Rare (Italy) is the representative body of the community of people with rare diseases. It has over 150 member associations, which are constantly growing.
- Parent Project per la Ricerca sulla Distrofia Muscolare (Italy), an association of patients and parents with children affected by Duchenne and Becker muscular dystrophy.



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TRANSNATIONAL MEETINGS



KICK-OFF MEETING

The online kick-off meeting of the initiative was held on March 29th, 2022. The partnership presented the dissemination plan of the IGTV: YOUTH WITH COURAGE and planned the different strategies that will be followed.

FIRST TRANSNATIONAL MEETING

The first transnational took place in Madrid, on May 26th, with the participation of all the partners. After analysing the progress so far, they continue with the development of the project.

The partnership had the chance to met the second vice-president of the Congress of Deputies, Ms. Ana Pastor, who listened attentively to the objectives of the initiative.



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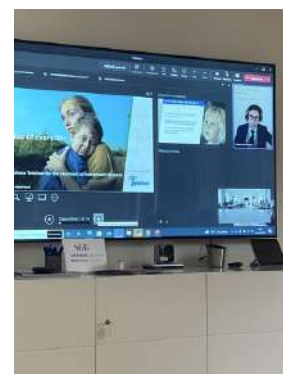
SECOND TRANSNATIONAL MEETING

Toulouse was the venue chosen to hold the second transnational meeting of the project, on July 22nd. Aiming to improve the stats on social media, the partners decided to develop a campaign to encourage people suffering from rare diseases to share their own story. Besides, the consortium will launch a questionnaire to evaluate the impact of the IGTV: YOUTH WITH COURAGE.



THIRD TRANSNATIONAL MEETING

The third transnational meeting was held in Rome on October 24th. The partnership analyzed the progress and coordinated the following steps. The audience in the different social media profiles has increased considerably since the last meeting.



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FOURTH AND FINAL TRANSNATIONAL MEETING

[The Erasmus+ YOUNG PEOPLE WITH RARE DISEASES held its 4th and final transnational meeting in Barcelona on January 23rd. The partnership discussed the results and analysed all the activities carried out within the project.



The initiative YOUTH WITH COURAGE has shared a total of 28 videos with the testimonies of young people affected by rare diseases and muscular dystrophies.

The organizations involved in the project would like to thank you the protagonists of the initiative for their willingness and collaboration. They have set an example to young people and society with their value to face life. We would also like to thank you all the people that have supported us in the different stages of the project.

The partnership concluded that the project has been a very positive and enriching experience for all the organizations,



YOUTH WITH COURAGE

A virtual environment on Instagram where the patients explain how they defeat the daily barriers that most of us do not get to perceive.



CAROLINA

Carolina is 28 years old and suffers from Friedreich's Ataxia. Dancing is one of her greatest passions.

ADRIÁN

Adrián studies Videogames design and development. He suffers from Spastic Paraplegia.



NICOLE

Nicole manages and presents a podcast in which she interviews people with rare diseases. She suffers from Systemic Mastocytosis.



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ROBERTO

Roberto, musician and composer, suffers from Becker Muscular Dystrophy.

JONATHAN

Jonathan is the captain of the French wheelchair rugby team. He suffers from Charcot-Marie-Tooth type 1



LAURA

Laura has a rare disease called Arthrogryposis Multiplex Congenita. She highlights the importance of professionalized personal assistance.

ALICE

Alice runs a program called "Women and Disability". She suffers from a rare disease called Microdeletion of Chromosome 22.



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JUAN

Juan suffers from Congenital Disorders of Glycosylation (CDG). His mother claims that all the people suffering from a very serious disease deserve a treatment.

AUDREY

Audrey was diagnosed with Charcot Marie Tooth when she was three and a half years old. She is now starting her own business in textile design.



MICHELE

Michele lives in Rome and he is passionate about football and Formula1. He lives with Duchenne Muscular Dystrophy (DMD).

MINA

Mina lives with a rare disease called DiGeorge's syndrome or velo-cardio-facial syndrome. When she was a teenager, she was also diagnosed with scoliosis idiopathic.



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MIKEL

Mikel, 22 years old, has a degenerative neuromuscular disease, called Spinal Muscular Atrophy Type II.

ALEX

Alex is the vicepresident of the association CMT France, which helps patients suffering from Charcot Marie Tooth disease, the disease he also suffers.



ALICIA

Alicia is a young woman of 22 years old who suffers from muscular dystrophy. Her mother points out that society doesn't worry about rare disease



SAMUELE

Samuele, 21 years old, studies Mechanical Engineering at La Sapienza and is passionate of hockey. He also suffers Duchenne muscular dystrophy (DMD).



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SARA

Sara is 24 years old and she suffers a genetic disproportion of muscle fiber types, due to a mutation of RHNO gene.

LAURA

Laura suffers the Charcot Marie Tooth disease (CMT). She was diagnosed with this disease when she was 7 years old.



MÓNICA

Mónica is 21 years old and she suffers three rare syndromes: Willkie syndrome, Nutcracker syndrome and May-Thurner syndrome.

ANTONIO

Antonio is a content creator. He is 19 years old, and he suffers Becker muscular dystrophy.



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OLIVIA

Olivia is 14 years old and she suffers the Charcot Marie Tooth degenerative disease. In the future she wants to study biomedicine.

DAVIDE

Davide was diagnosed with Williams syndrome when he was a few months old. Sports have helped him to overcome several barriers.



ANDRÉS

Andrés have Spastic Paraparesia. HE loves superheroes and his biggest dream is to become as fast as a lightning.



CRISTINA

Cristina suffers Phenylketonuria, a rare disease that can lead to intellectual and motor disorders. She encourages society to support people with rare diseases.



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JACOPO

Jacopo studies Communication Science at the University of Padua. He is affected by Duchenne Muscular Dystrophy (DMD).

MATTEO

Matteo is enrolled in the Agricultural Science and Technologies degree course in Grugliasco. He suffers Duchenne Muscular Dystrophy (DMD).



LETHICIA

Lethicia is 29 years old, and she suffers from Congenital Hypophosphatasia, an absence or low levels of serum alkaline phosphatase.



NICO

Nico is a researcher of the Institut national de la santé et de la recherche médicale looking for therapies for the Charcot Marie Tooth disease.



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A circular portrait of a young boy with short brown hair, wearing an orange polo shirt, looking slightly upwards and to the left. The portrait is set against a black background and is framed by a light green circular border. To the left of the portrait is a light purple rectangular background with a green arrow pointing right.

BRUNO

Bruno is 13 years old, and he suffers a disease called non-progressive congenital Ataxia.

ROBERTA

Roberta is 23 years old and she suffers Ataxia, a rare disease which have many different variants.



YOUTH
WITH
COURAGE



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STATS ON SOCIAL MEDIA

YOUTUBE

Contenido	Visualizaciones ↓	Tiempo de visualización (horas)	Duración media de las visualizaciones	Impresiones	Porcentaje de clics de las impresiones
<input type="checkbox"/> Total	3.976	195,3	2:56	11.466	4,6 %
<input type="checkbox"/> YOUTH WITH COURAGE: Michele	600 15,1 %	12,3 6,3 %	1:13	174	8,6 %
<input type="checkbox"/> YOUTH WITH COURAGE: Jacopo & Matteo	489 12,3 %	41,7 21,4 %	5:07	913	3,2 %
<input type="checkbox"/> YOUTH WITH COURAGE: Samuele	372 9,4 %	27,4 14,0 %	4:24	674	4,8 %
<input type="checkbox"/> YOUTH WITH COURAGE: Alice	371 9,3 %	11,4 5,8 %	1:50	501	3,8 %
<input type="checkbox"/> YOUTH WITH COURAGE: Antonio	333 8,4 %	21,5 11,0 %	3:52	1.645	1,1 %
<input type="checkbox"/> YOUTH WITH COURAGE: Juan	313 7,9 %	25,7 13,2 %	4:56	451	4,7 %
<input type="checkbox"/> YOUTH WITH COURAGE: Olivia	273 6,9 %	19,9 10,2 %	4:22	1.008	3,6 %
<input type="checkbox"/> YOUTH WITH COURAGE: Mónica	232 5,8 %	12,7 6,5 %	3:17	1.082	4,0 %

Fuente de tráfico > Fuentes externas	Visualizaciones ↓	Tiempo de visualización (horas)	Duración media de las visualizaciones
<input type="checkbox"/> Total	2.555	155,5	3:39
<input type="checkbox"/> Facebook	1.503 58,8 %	100,7 64,8 %	4:01
<input type="checkbox"/> WhatsApp	596 23,3 %	33,1 21,3 %	3:20
<input type="checkbox"/> Instagram.com	44 1,7 %	3,4 2,2 %	4:38
<input type="checkbox"/> YouTube	33 1,3 %	0,2 0,2 %	0:24
<input type="checkbox"/> Twitter	29 1,1 %	1,0 0,6 %	1:59
<input type="checkbox"/> Google Search	26 1,0 %	1,6 1,1 %	3:45

Área geográfica	Visualizaciones ↓	Tiempo de visualización (horas)	Duración media de las visualizaciones
<input type="checkbox"/> Total	3.976	195,3	2:56
<input type="checkbox"/> Italia	1.969 49,5 %	111,3 57,0 %	3:23
<input type="checkbox"/> España	644 16,2 %	41,3 21,2 %	3:51
<input type="checkbox"/> Argentina	13 0,3 %	0,2 0,1 %	1:06
<input type="checkbox"/> Francia	10 0,3 %	0,1 0,0 %	0:31

Sexo del espectador ↓	Visualizaciones	Duración media de las visualizaciones	Porcentaje medio visto	Tiempo de visualización (horas)
<input type="checkbox"/> Mujer	49,7 %	2:45	28,6 %	60,2 %
<input type="checkbox"/> Hombre	50,3 %	1:48	18,9 %	39,8 %
<input type="checkbox"/> Especificado por el usuario	—	—	—	—

INSTAGRAM

Topic	Views
Story of Juan	1.495
Story of Sara	983
Story of Olivia	547
Story of Davide	349
Story of Mina	250
Story of Bruno	210
Story of Roberta	208
Summary of December - January	208

MEDIA:

- 824 VIEWS
- 13,5 likes

TOTAL:

- 22.267 VIEWS



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FACEBOOK

Todo el contenido

Publicaciones e historias Tipo de contenido: multi... Filtrar Borrar Buscar por texto o... Colum...

Título	Alcance	Me gusta y reacciones
We are excited to share the new lo... Youthwithcourage	1880 Cuentas del Centro de ...	23 Reacciones
♥ Jacopo & Matteo are two fri... Youthwithcourage	1828 Cuentas del Centro de ...	339 Reacciones
Toulouse was the chosen venue to ... Youthwithcourage	1326 Cuentas del Centro de ...	31 Reacciones
+ Mina Chiaravalle lives with a rare ... Youthwithcourage	1058 Cuentas del Centro de ...	13 Reacciones
Alice Colombo suffers from a rare ... Youthwithcourage	982 Cuentas del Centro de ...	20 Reacciones
"The figure of the personal assista... Youthwithcourage	828 Cuentas del Centro de ...	9 Reacciones

Resultados

Alcance de la página de Facebook

8187 ± 100 %



Visitas a la página de Facebook

519 ± 100 %



TWITTER

	Tweets	Impresiones	Visitas	Menciones	Seguidores
Abril	22	2.536	8.095	3	8
Mayo	19	2.714	4.730	13	0
Junio	9	1.596	1933	4	0
Julio	8	929	1.190	3	0
Agosto		308	121	1	0
Septiembre	11	1.738	1.825	5	1
Octubre	7	929	957	2	1
Noviembre	8	825	631	2	2
Diciembre	13	1.149	1.197	5	1
Enero	5	698	590	1	0



MEDIA PARTNERS



29.045 views / 1.169 feedback / 4.170 impressions



26.402 views / 4.909 feedback / 30.160 impressions



4.620 views / 1.213 feedback / 15.180 impressions



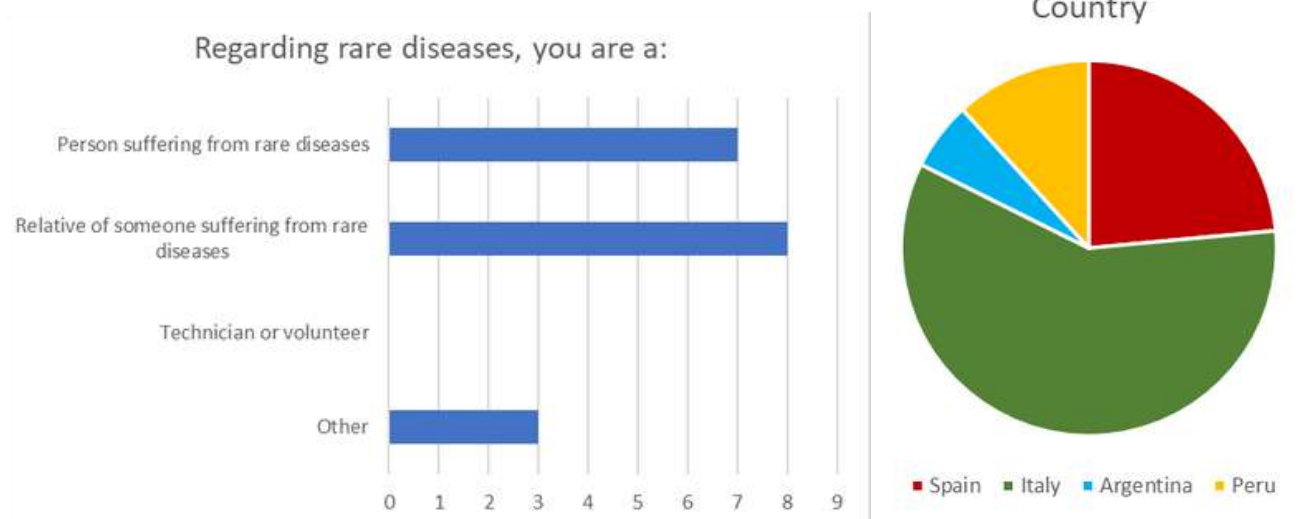
5.612 views / 371 feedback / 23.147 impressions



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EVALUATION QUESTIONNAIRE



From the evaluation questionnaire developed by the partnership to analyse the impact of the project we have drawn the following conclusions:

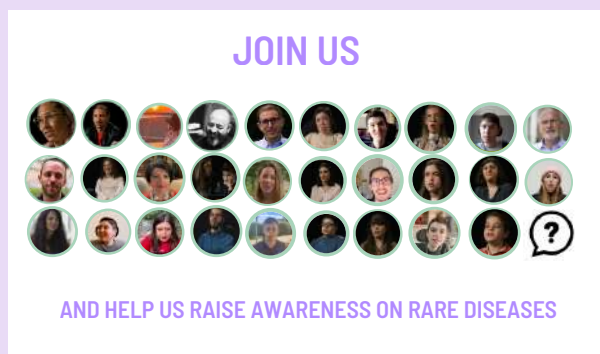
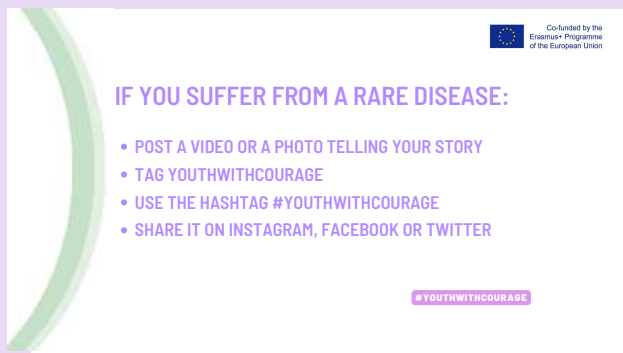
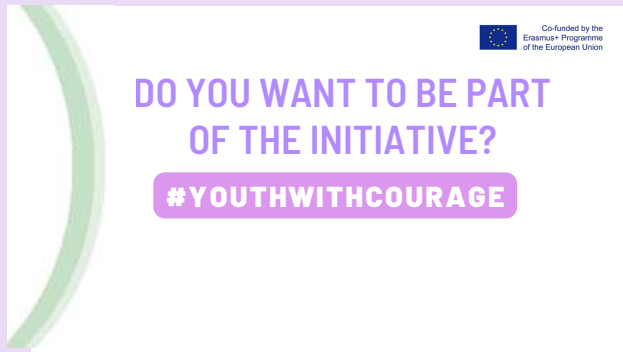
- All the respondents agree that this kind of initiatives benefits people suffering from rare diseases. They also affirm that they have learnt something while watching the videos. Courage and empathy, the importance of research and how to overcome difficulties are some of their answers.
- As to the question concerning inclusiveness, they point out that it is important to carried out similar initiatives to YOUTH WITH COURAGE to continue raising awareness among society. Also, they consider that it is necessary to increase the funding and training of society regarding rare diseases.



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SUSTAINABILITY CAMPAIGN



SOCIAL MEDIA



[youthwithcourage](https://www.youtube.com/youthwithcourage)



[@youthwithcourage](https://www.instagram.com/youthwithcourage)



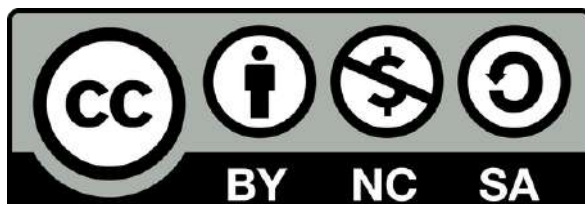
[youthwithcourage](https://www.facebook.com/youthwithcourage)



[@youthwccourage](https://twitter.com/youthwccourage)



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