

**D7.7 Video explaining new knowledge to individuals with DS,
their families, clinicians, general practitioners and scientists**

**WP7 – Dissemination, communication, exploitation and
guideline development**



**GENE OVERDOSAGE AND COMORBIDITIES DURING THE
EARLY LIFETIME IN DOWN SYNDROME**

Disclaimer

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Table of Contents

1	Acronyms and definitions.....	4
2	Related objectives of the Description of Action	5
3	Executive Summary.....	5
3.1	Methodology.....	5
3.2	Main results	5
3.3	Progress beyond the state-of-the-art.....	5
4	Deliverable report.....	6
4.1	Challenge	6
4.2	Methodology.....	6
4.2.1	Introductory videos and Work Package (WP) videos	6
4.2.2	Results videos.....	6
4.2.3	Animation-style project video	6
4.3	Results.....	7
4.3.1	Introductory video(s)	7
4.3.2	Work Package videos	8
4.3.3	Results videos.....	11
4.3.4	Animation-style project video	12
5	Conclusion	13
6	References.....	14
7	Appendix.....	15

1 Acronyms and definitions

CERBM	Centre Européen de Recherche en Biologie et Médecine
concentris	concentris research management GmbH
CRG	Fundacio Centre de Regulario Genomica
D	Deliverable
DE	German
DoA	Description of Action
DS	Down Syndrome
EC	European Commission
EDSA	European Down Syndrome Association
EN	English
ES	Spanish
FR	French
IT	Italian
IJL	Institut Jerome Lejeune
IMIM	Fundacio Institut Mar D Investigacions Mediques
M	Project month
PM	Person months (invested human resources)
QMUL	Queen Mary University of London
WP	Work package

2 Related objectives of the Description of Action

Targeted towards all stakeholder groups, but primarily to people living with Down Syndrome (DS) and their caregivers and relatives, this deliverable (D7.7 - Video explaining new knowledge to individuals with DS, their families, clinicians, general practitioners and scientists; due by project month 60, December 2024) is related to the following two objectives end tasks of work package 7 (WP7):

- Objective 1: To disseminate the results of GO-DS21 to relevant stakeholders (Task 1)
- Objective 2: To disseminate the results to the scientific, healthcare, pharmaceutical and policy sectors and foster interaction and exchange with DS organizations (Task 2)

3 Executive Summary

3.1 Methodology

To disseminate our project goals and explain new knowledge generated by the GO-DS21 consortium to individuals with DS and their relatives, but also to clinicians, general practitioners and scientists, we first created a GO-DS YouTube channel, and then — produce videos for different audience throughout the duration of the project. These include different types of formats and methods, including a self-recorded introductory video by coordinator, Prof. Yann Herault (CERBM), explanatory videos in laboratory settings in which work package (WP) leaders provide an overview of their WP's goals and methods, results videos in form of recorded lectures and talks, and a final animation-style summary video to convey new knowledge to our stakeholder community. Each video was uploaded to the GO-DS21 YouTube channel, embedded on the GO-DS1 project website, and promoted via social media channels. Here we selected first X and LinkedIn.

3.2 Main results

The GO-DS21 consortium has been very active and produced **14 distinct videos** presenting the project's goals, methods, and outcomes for various target groups. The videos can be viewed on the [GO-DS21 YouTube channel](#), have been embedded into the [GO-DS21 project website](#), and were promoted on social media ([X](#) and [LinkedIn](#)). **Three introductory videos** explain the project goals in the form of a short video by the coordinator, a longer version of the same video, and provide an overview of the clinical trial. **Seven WP videos** explain the objectives, concept, and methodology behind the different WPs, **three results videos** have been published to present major outcomes of GO-DS (specifically with regard to thyroid function and obesity, a common comorbidity of DS), and finally, the [animation-style project video](#) provides an overview of the entire project, its objectives, main outcomes and new knowledge.

3.3 Progress beyond the state-of-the-art

The GO-DS21 consortium did not only produce one video (fulfilling the requirements of D7.7), but established a **GO-DS21 YouTube channel** (<https://www.youtube.com/@GO-DS21>) at the beginning of the project, starting with the introductory video, and has by now published **14 videos in total**. While this goes beyond the state of the art and what is stated in the Description of Action (DoA), this approach was mainly chosen because it satisfies the different needs, interests, and levels of expertise of **different target groups**, e.g. patients and their relatives versus the general public, scientific experts, and medical professionals.

4 Deliverable report

4.1 Challenge

The main challenge was to convey the overall goal, the project objectives, and major outcomes of GO-DS21 to various target groups in different European languages as well as different levels of scientific detail and easy versus complex language. To address the different target groups properly, the consortium purposefully produced videos in English, but also in French, Spanish, Italian, and German. For the [final project video](#), a children-friendly animation style and easy language had to be chosen, whereas the three results videos – for example – were targeted more towards a scientific audience.

4.2 Methodology

The following approaches and methodologies were used to produce 3 different types of videos.

4.2.1 Introductory videos and Work Package (WP) videos

The introductory videos are **self-recorded monolog videos** and provide an overview of the project's goals, its objectives, and the scope of the GO-DS21 clinical trial. They are targeted towards the general public, individuals living with DS, their caregivers and families, but also towards the scientific community. The videos have been recorded in French, English, Italian, Spanish, and German language, but a big benefit of the GO-DS21 YouTube channel is that it allows for automatic subtitle translations into English as well as other European languages. The [short version](#) of the first introductory video features only the **project coordinator, Prof. Yann Herault (IGBMC/CERBM)**, while the [long version](#) of the introductory video also features the WP leaders. The [video about GO-DS21's clinical trial](#) features the study coordinator **Dr. Anne Hiance-Delahaye** (from consortium partner **IJL**), as well as individuals with DS and family members. The [seven WP videos](#) feature the **WP leaders** and, in some cases, their respective team members.

4.2.2 Results videos

The [three results videos](#) are **recorded conference talks / presentations** with GO-DS21 researchers as speakers / presenters. All of the results videos are in English language and are primarily targeted to scientists and clinicians, but also towards a well-educated general public and relatives of individuals living with DS. Again, YouTube allows for automatic translation of the English subtitles into all other European languages.

4.2.3 Animation-style project video

The **animation-style project video** [“Let us GO-DS21: Gene Overdosage & Early Life Comorbidities in Down Syndrome”](#) was undertaken in the framework of WP7 of the GO-DS21 project. Main partners participating in the production were HMRI and CRG. The purpose was to disseminate the aims of the project and the scientific approach applied to achieve them. The potential audience were families and subjects with Down syndrome. The video was designed using **easy lay language and entertaining, children-targeting graphics** that had already proved to be efficient in a related project. The following steps were followed to develop and produce the video:

- A tentative script was produced by partner IMIM and shared with all partners for feed-back
- The script was reviewed by IMIM, CRG, and the project coordinator (Prof. Yann Herault, CERBM)
- The script was then discussed with Karavan Films (<https://karavanfilms.com/en/>)
- A detailed storyboard (see **Appendix**) was submitted by Karavan films for review by the consortium
- The storyboard was reviewed by IMIM, CRG, and the GO-DS21 project coordinator
- The video was produced, including audio translations and subtitles in several European languages
- The animation-style aesthetics of the video is similar to the one used in comparable videos that are used to inform subjects with DS about ongoing research and invite them to participate in clinical studies (e.g. the ones developed in the framework of the Horizon2020-funded ICOD project)

4.3 Results

Below are the videos that resulted from the WP7 dissemination strategy and our approach to inform different types of stakeholders and target groups via different video formats about the aims, approach, and results of the GO-DS21 project.

4.3.1 Introductory video(s)

One long (11 min) and one short (3 min) introductory video have been produced.

Primary target audience: general public, research community, clinicians

Video title(s):	<i>GO-DS21 - Introduction (short version)</i> <i>GO-DS21 - A pan-European research project addressing common Down Syndrome comorbidities (long version)</i>
Video URL(s):	https://youtu.be/VOVONgJdWuY (short), https://youtu.be/OqkJIGijqdw (long)
Video length(s):	2:58 min (short version) and 11:23 min (long version)
Publication date:	18 March 2022
Language(s):	French (FR), and – in the long version – also English (EN), German (DE), Italian (IT), and Spanish (ES)
Video description:	https://go-ds21.eu

Watch the GO-DS21 consortium members explain in this video an ambitious pan-European project that investigates the underlying mechanisms and etiology of common Down Syndrome (DS) comorbidities.

Clinicians, pathophysiologists, integrative bioinformaticians, and artificial intelligence computer scientists working to unravel intrinsic and extrinsic mechanisms that impact DS comorbidity (focusing on obesity and intellectual disability). The examination of the pathways and mechanisms involved in comorbidities and multi-morbidities that induce the coexistence of two or more diseases in an individual is of major importance for the effective treatment of patients suffering from DS, obesity, and mental disorders.

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<https://www.concentris.de>



(short version of intro-video, click on image to play)



(long version of intro video, click on image to play)

Partner IJL, spearheaded by clinical study coordinator **Dr. Anne Hiance-Delahaye**, produced a patient-targeted video together with individuals with DS and their family members.

Target audience: Individuals with DS and their family members and relatives

Video title: *Clinical Trial GO-DS21 in the Jerome Lejeune Institut*

Video URL: <https://youtu.be/TWKI7JNtQ8g>

Video length: 4:06 min

Publication date: 29 April 2022 (video in French (FR) with English (EN) subtitles)

Description: GO-DS21 started in June 2021 and is expected to last 3 years. In each of the 3 investigating countries, 100 volunteers – all with trisomy 21 and aged 12-45 years old – will be enrolled on the study.



(clinical trial video, click on image to play video)

4.3.2 Work Package videos

The following seven GO-DS21 work package (WP) videos have been recorded and published on YouTube in April 2022 to inform the general public, scientists, and clinicians about the aims and objectives of each WP.

Target audience (all): general public, research community, clinicians

Language (all): English (EN)

Subtitles (all): English (EN)

Video description (all): <https://go-ds21.eu>


Watch the GO-DS21 consortium members explain in this video an ambitious pan-European project that investigates the underlying mechanisms and etiology of common Down Syndrome (DS) comorbidities.

Clinicians, pathophysiologists, integrative bioinformaticians, and artificial intelligence computer scientists working to unravel intrinsic and extrinsic mechanisms that impact DS comorbidity (focusing on obesity and intellectual disability). The examination of the pathways and mechanisms involved in comorbidities and multi-morbidities that induce the coexistence of two or more diseases in an individual is of major importance for the effective treatment of patients suffering from DS, obesity, and mental disorders.


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<https://www.concentris.de>


1. Video title: *GO-DS21 WP1 - Elucidating age-related comorbidity patterns in Down syndrome*
Video URL: <https://youtu.be/G5SW-29t4sc?si=5Eqn40wxYI1Nfrl1>
Video length: 2:12 min
Publication date: 7th April 2022 (video in English, EN)
2. Video title: *GO-DS21 WP2 - Influence of global Hsa21 gene dosage and diet/exercise/stress on comorbidity*
Video URL: https://youtu.be/X05plQ7Yuts?si=AVKa_YQqMEEERnCW
Video length: 0:42 min
Publication date: 8th April 2022 (video in English, EN)
3. Video title: *GO-DS21 WP3 - Validation of the role of hypothesis-driven genes between obesity and ID*
Video URL: <https://youtu.be/Ltlv5jSMHMc?si=2ZhcxNwzhxx4B2L2>
Video length: 1:12 min
Publication date: 7th April 2022 (video in English, EN)
4. Video title: *GO-DS21 WP4 - Identification of mechanisms for DS obesity and intellectual disability comorbidity*
Video URL: https://youtu.be/a-P22_bz_1o?si=tJrSlO4quTWeHKaw
Video length: 1:37 min
Publication date: 7th April 2022 (video in English, EN)
5. Video title: *GO-DS21 WP5 - Transcriptomic and epigenetic analyses for mental and physical comorbidities in DS*
Video URL: <https://youtu.be/FN2qCF-71Lo?si=4EW5PhOMeDQ2VrZV>
Video length: 0:46 min
Publication date: 7th April 2022 (Video in German, DE)
6. Video title: *GO-DS21 WP6 - Building the “Down syndrome comorbidity network”*
Video URL: https://youtu.be/C81kQN0x_oA?si=wTWqNw1RZ1y_Xtq7
Video length: 0:57 min
Publication date: 7th April 2022 (video in Italian, IT)
7. Video title: *GO-DS21 WP7 - Dissemination, communication, exploitation and guideline development*
Video URL: <https://youtu.be/iQaXfncTcV4?si=4kFV24YcR5JfiZn7>
Video length: 1:06 min
Publication date: 7th April 2022 (Video in Spanish, ES)



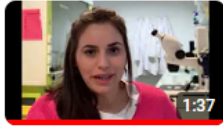
GO-DS21 WP1 – Elucidating age-related comorbidity patterns in Down syndrome
GO-DS21 • 67 views • 2 years ago




GO-DS21 WP2 – Influence of global Hsa21 gene dosage and diet/exercise/stress on comorbidity
GO-DS21 • 58 views • 2 years ago




GO-DS21 WP3 – Validation of the role of hypothesis-driven genes between obesity and ID
GO-DS21 • 25 views • 2 years ago




GO-DS21 WP4 – Identification of mechanisms for DS obesity and intellectual disability comorbidity
GO-DS21 • 20 views • 2 years ago



GO-DS21 WP5 – Transcriptomic and epigenetic analyses for mental and physical comorbidities in DS
GO-DS21 • 22 views • 2 years ago



GO-DS21 WP6 – Building the “Down syndrome comorbidity network”
GO-DS21 • 29 views • 2 years ago



GO-DS21 WP7 – Dissemination, communication, exploitation and guideline development
GO-DS21 • 20 views • 2 years ago

(screenshot of YouTube Playlist “GO-DS21 Work Packages”, click on the screenshot to open the Playlist)

4.3.3 Results videos

The following four GO-DS21 results videos have been recorded and published on YouTube between April 2022 and March 2024.

Target audience (all): research community, clinicians, well-educated relatives (of individuals with DS)
Language: English (EN)
Subtitles: English (EN)

1. Video title: *Thyroid function in Down syndrome - Dr. Li Chan, from Queen Mary University of London*
Video URL: <https://youtu.be/zsV525cC4Fk>
Video length: 10:23 min
Publication date: 22 March 2023 (in English, EN)
Description: Presented at the World Down Syndrome Day 2023 event in London.
2. Video title: *Thyroid function in Down syndrome - Dr Kyriacos Gregoriou, from Queen Mary University of London*
Video URL: <https://youtu.be/ilyAOrheB1g>
Video length: 2:35 min
Publication date: 17 March 2024 (in English, EN)
Description: Dr Kyriacos Gregoriou, from Queen Mary University of London, talks about the research conducted at Prof Li Chan's lab and the symptoms of hypo- and hyperthyroidism at the World Down Syndrome Day 2024 celebration, organised by researchers from Queen Mary University of London, University College London, King's College London and The Crick Institute for people with Down Syndrome and their families and carers at the Crick institute on 16 March 2024.
3. Video title: *Obesity in Down syndrome - Prof Li Chan, from Queen Mary University of London*
Video URL: https://youtu.be/JQdKpL_oSXA
Video length: 13:17 min
Publication date: 17 March 2024 (in English, EN)
Description: Professor Li Chan, from Queen Mary University of London, talks about obesity in Down syndrome and the research conducted by GO-DS21 consortium at the World Down Syndrome Day 2024 celebration, organised by researchers from Queen Mary University of London, University College London, King's College London and The Crick Institute for people with Down Syndrome and their families and carers at the Crick institute on 16 March 2024.



(YouTube thumbnails of results videos, click on respective image to play the video)

4.3.4 Animation-style project video

Target audience: People living with DS, their families, and their relatives

Objective: to describe the main aims of the GODS-21 project and the scientific approach applied to understand how lifestyle choices, like exercise and diet, impact the health of subjects with Down syndrome and to get insight into how these factors influence weight management, diabetes, and other health conditions.

Video title: ***Let us GO-DS21: Gene Overdosage & Early Life Comorbidities in Down Syndrome***

Video URL: <https://youtu.be/zhobkgkWh6A>

Video length: 2:56 min

Publication date: 7th June 2024

Video Language: English (EN)

Subtitles: English (EN)

Video description: <https://go-ds21.eu/>

We are pleased to introduce the GO-DS21 initiative aiming at understanding comorbidities in Down syndrome and suggest alternatives to reduce their consequences and improve the quality of life of individuals with Down syndrome.

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(animation-style project video, click on image to play)

5 Conclusion

The videos contributed substantially to the dissemination goals of the GO-DS21 consortium and helped to increase the recruitment numbers of the GO-DS21 clinical trial. Taken together, all GO-DS21 videos have by November 10th 2024 been **watched more than 800 times**, and the analytics area of the GO-DS21 YouTube channel indicates **more than 6,100 impressions** (people reached). See **Figure 1** below for the monthly timeline of video views (purple) and video impressions (green) from March 2022, when the YouTube channel was established, to November 2024, when this report was written and submitted to the funding agency, the European Commission (EC).

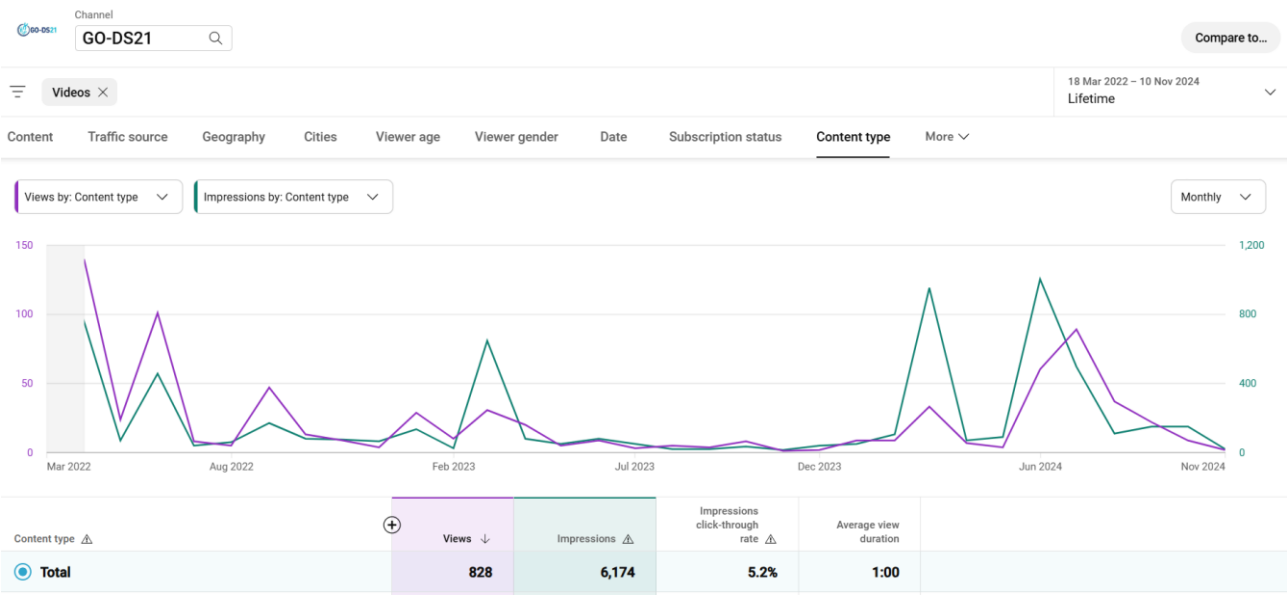


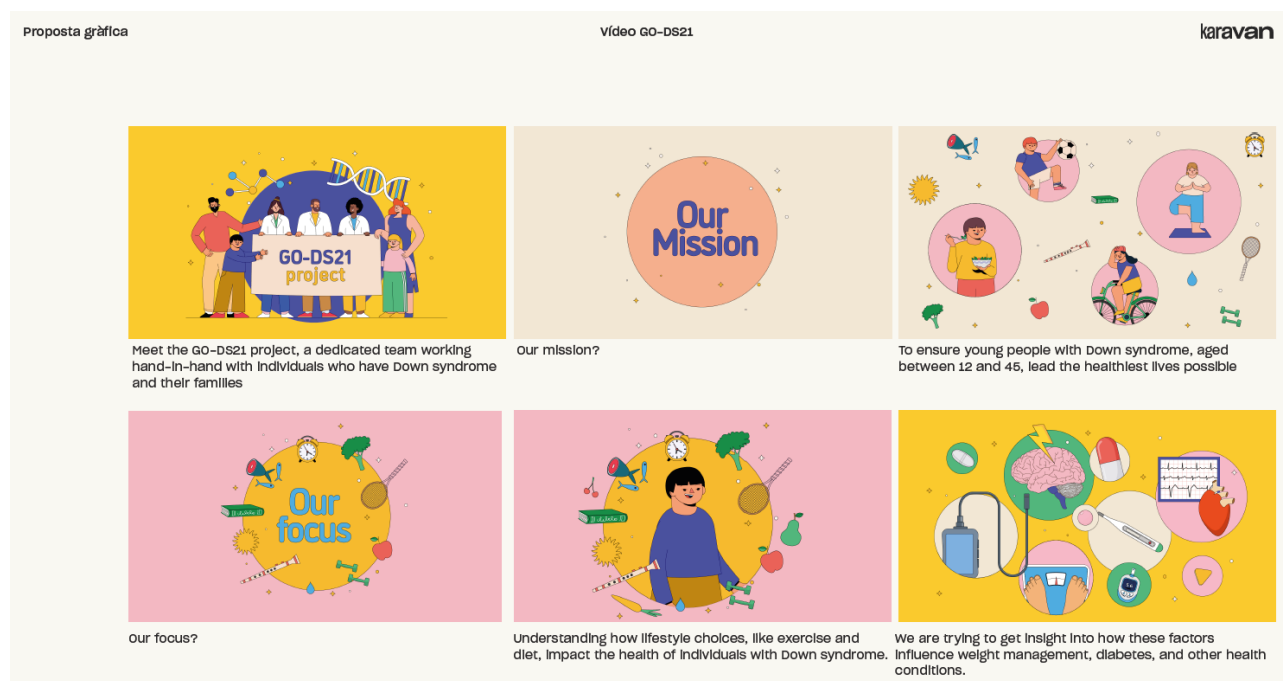
Figure 1. Screenshot of the overall impact of the GO-DS21 videos as of 10th November 2024 since the project’s YouTube channel was created on 18th March 2022. The purple line indicates the number of video views, the green line indicates the number of video impressions (“impressions” means how many people were reached with the videos or had the videos displayed on their computer-, tablet-, or smart phone screens while surfing the internet).

6 References

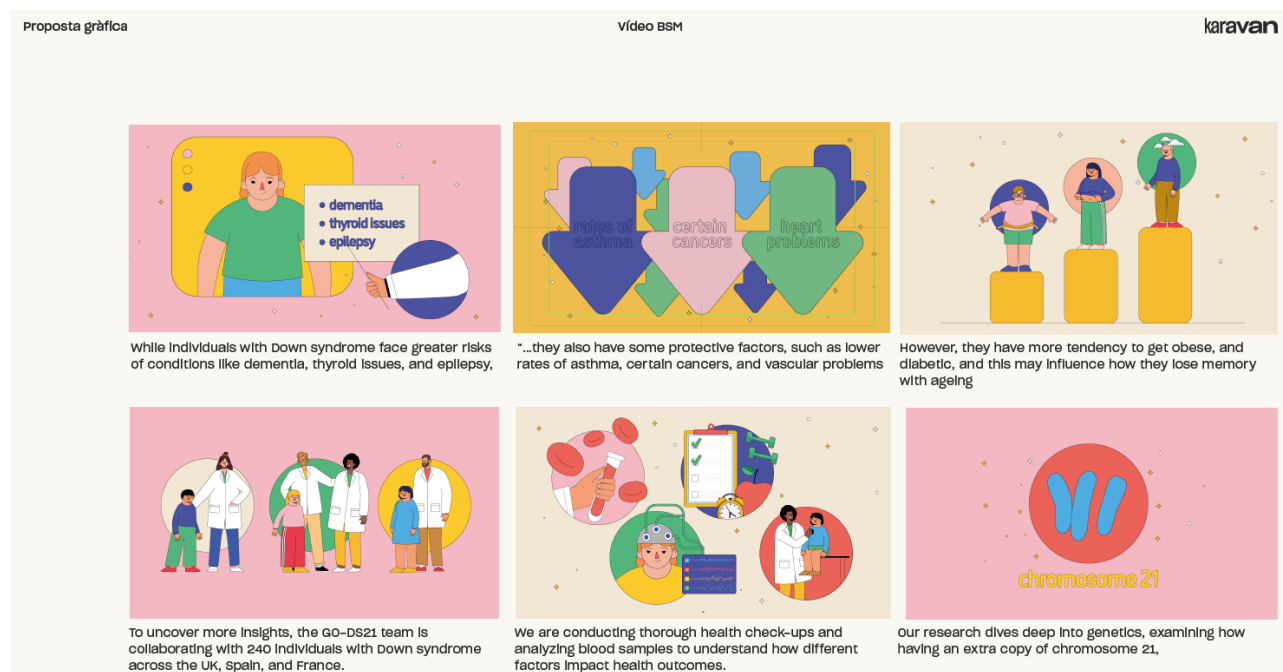
- **GO-DS21 YouTube Account**
<https://www.youtube.com/@GO-DS21>
- **Introductory video:**
GO-DS21 - A pan-European research project addressing common Down Syndrome comorbidities
<https://youtu.be/OqkIJijqdw?si=IQCXltuqRpH2XFxA>
- **Project video**
Let us GO-DS21: Gene Overdosage & Early Life Comorbidities in Down Syndrome
<https://youtu.be/zhobkgkWh6A?si=EJ-1s9b0RjPBzgNJ>
- **Work Package videos:**
 - *GO-DS21 WP1 - Elucidating age-related comorbidity patterns in Down syndrome*
<https://youtu.be/G5SW-29t4sc?si=5Eqn40wxYl1Nfrl1>
 - *GO-DS21 WP2 - Influence of global Hsa21 gene dosage and diet/exercise/stress on comorbidity*
https://youtu.be/X05plQ7Yuts?si=AVKa_YQqMEEERnCw
 - *GO-DS21 WP3 - Validation of the role of hypothesis-driven genes between obesity and ID*
<https://youtu.be/Ltlv5jSMHMc?si=2ZhcxNwzhxx4B2L2>
 - *GO-DS21 WP4 - Identification of mechanisms for DS obesity and intellectual disability comorbidity*
https://youtu.be/a-P22_bz_1o?si=tJrSIO4quTWeHKaw
 - *GO-DS21 WP5 - Transcriptomic and epigenetic analyses for mental and physical comorbidities in DS*
<https://youtu.be/FN2qCF-71Lo?si=4EW5PhOMeDQ2VrZV>
 - *GO-DS21 WP6 - Building the “Down syndrome comorbidity network”*
https://youtu.be/C81kQN0x_oA?si=wTWqNw1RZ1y_Xtq7
 - *GO-DS21 WP7 - Dissemination, communication, exploitation and guideline development*
<https://youtu.be/iQaXfncTcV4?si=4kFV24YcR5JfiZn7>
- **Results videos:**
 - *Clinical Trial GO-DS21 in the Jerome Lejeune Institut*
https://youtu.be/TWKl7JNtQ8g?si=UCz_rHjiu32Qlas
 - *Obesity in Down syndrome - Prof Li Chan from Queen Mary University of London*
https://youtu.be/JQdKpL_oSXA?si=l_oVlnCC4k-n86_k
 - *Thyroid function in Down syndrome - Dr. Li Chan from Queen Mary University of London*
https://youtu.be/zsV525cC4Fk?si=eNpa_7y30mMmak4-
 - *Thyroid function in Down syndrome - Dr Kyriacos Gregoriou from Queen Mary University of London*
<https://youtu.be/ilyAO rheB1g?si=YUzoudNar3E78H6Q>

7 Appendix

Story Board for production of the animation-style project video (by Karavan Films)



Page 1

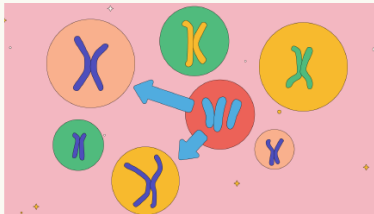


Page 2

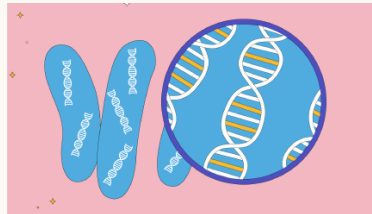
Proposta gráfica

Video BSM

karavan



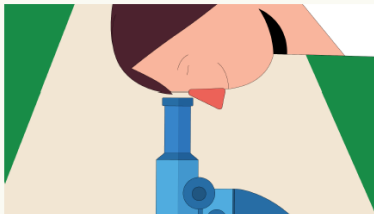
the cause of Down syndrome, affects the rest of genes and molecules in the body,



to understand, like in a puzzle, which are the most important pieces



By studying both human subjects...



...and specially engineered mouse models,

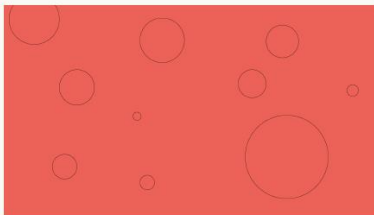


Page 3

Proposta gráfica

Video BSM

karavan



we aim to discover biomarkers –important clues about health risks– and potential treatments.



But It's not just genetics, stress plays a role too.



When stressed, the body releases hormones that can influence appetite, leading to unhealthy eating habits and weight gain.



Our team is Investigating how social stress in individuals with down syndrome can contribute to obesity development.




Meanwhile, Perha Pharmaceuticals is developing a promising drug called Leucettinb-21.


Page 4

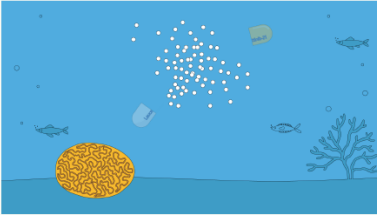
Proposta gráfica

Video BSM

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Inspired by a compound found in a sea sponge,

this drug targets a specific gene associated with cognitive issues in Down syndrome, and possibly also diabetes







Early tests have shown improvements in learning and memory in animal models.

Through collaboration, innovation, and dedication, the GO-DS21 project and our team is paving the way for brighter, healthier futures for individuals with Down syndrome

Page 5

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Page 6