

First report on networking, public engagement and Communication activities

Deliverable 11.3

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Executive summary

The aim of the Deliverable 11.3 “First report on networking, public engagement and communication activities” is to describe the dissemination and communication activities of the UPGRADE partners performed during the first year.

In the first 18 Months of the project, UPGRADE dissemination and communication activities are included in the “starting phase”. This phase has the objective of raising awareness of project’s activities, outputs and benefits through diverse channels to audiences. The Consortium is indeed elaborating the dissemination strategy, defining the project identity and producing promotional material. More information can be also found in the Deliverable 11.1 “Dissemination Plan”, available at the link <http://www.upgrade-h2020.eu/wp-content/uploads/2019/12/UPGRADE-D11.1-with-annex-SUBMITTED.pdf>

1 Dissemination objectives and tools

1.1 UPGRADE Dissemination Objectives

The main goal of WP11 is to ensure the interaction with stakeholders and the dissemination of the results of the project.

More in details, the specific objectives of this WP are:

- 1) create a network of researchers working in genome editing, vector delivery, immune evasion related to vector applying these therapies in models of muscle, hematopoietic, retinal and liver diseases, by means of proactive set of actions to transfer the scientific knowledge;
- 2) ensure the use of the technology platform to produce tailored genome editing toolboxes, through scientific publications;
- 3) ensure the effective knowledge transfer to early-career researchers, especially during the fourth and last year of the project, when two workshops and summer schools will be organized;
- 4) disseminate the results of the project to the largest audience possible (both specialists and non-specialists), including industry, decision makers (from the local to the EU Commission and government level), and citizens.

This deliverable represents an annual report on the dissemination and communication activities carried out by the UPGRADE Consortium. For the first year of project's implementation, the main objectives of WP11 were the following:

- Design and launch of the UPGRADE website
- Design and creation of the promotional material of the project (logo, overall presentation, press release, project fact sheet)
- Identification and organization of the stakeholders' groups
- Participation in events at national and international level to raise awareness and visibility of the project
- Establishing collaboration with similar EU funded projects
- Promotion of the project to press and media at local, national and European level

1.2 UPGRADE Dissemination Tools

1.2.1 Branding

In order to achieve a uniform design of all documents and a visual project identity, logos and document templates were developed during the first months of the project.

Following the project identity and style throughout the project communication activities ensured that the UPGRADE "product" is immediately recognisable by its audience.

Substantial effort has been made to ensure that the logo is taken up wherever relevant, including all project templates, posters, promotional material, website and social media.



Fig. 1 UPGRADE logo and colour scheme

1.2.2 Templates

Templates for different uses applying the UPGRADE brand identity were developed and distributed for mandatory use within the consortium in May 2019.

These templates include:

- Deliverable and Report
- Event Agenda
- Event Minutes
- Power point presentation, including title, content and acknowledgment slides

All communication and dissemination templates include the UPGRADE logo and the acknowledgement of EU funding given through the Horizon2020 programme.

Fig. 2 UPGRADE deliverable template

1.2.3 UPGRADE Website

The UPGRADE website (<http://www.upgrade-h2020.eu>) is the main source of information about the project to the outside world, with dedicated sections for the media, the public and other users. As reported in the Deliverable 11.2, (available under the link <http://www.upgrade-h2020.eu/wp-content/uploads/2019/12/UPGRADE-D11.2-Website.pdf>), the web site has been designed by FTELE. It contains information about the partners (location, skills, commitments and level of involvement), project outcomes (deliverable and milestone reports), research outputs (publications) and the dissemination material (leaflet, newsletter, brochures, and news). The UPGRADE website homepage has been published on 31st March 2019. Since then, it is continually evolving and kept dynamic.

1.2.4 Press Release and Media Presence

In addition to the project website, press releases are considered to be one of the most efficient tool for disseminating the project to a large number of recipients (media, organisations, initiatives and projects, academies, communities and networks) and are intended to help to promote the project at national and European level.

The first press release announcing the launch of the project was published on 15th February 2019 and can be found at the link <https://www.telethon.it/en/stories-and-news/news/from-telethon-foundation/tigem-and-sr-tiget-involved-in-upgrade-project-funded-by-the-european-union/>

UPGRADE project and its results have been featured at national and international level, both on internal and external platforms:

- "Using more-specific 'genetic scissors' may avoid problems associated with gene editing". Science Daily. <https://www.sciencedaily.com/releases/2019/03/190321130304.htm>
- "CRISPR is ascending again, after scientists find 'elegant' fix for cancer worry". STAT, Boston Globe. <https://www.statnews.com/2019/03/21/crispr-elegant-fix-for-cancer-worry/>
- "Editing genomico. CRISPR è una tecnologia sicura?". Osservatorio Terapie Avanzate

- <https://www.osservatorioterapieavanzate.it/terapie-avanzate/editing-genomico/editing-genomico-crispr-e-una-tecnologia-sicura>
- “La ricetta Telethon per l’editing genetico”. Le Scienze. http://www.lescienze.it/news/2019/03/27/news/telethon_crispr_editing-4349115/
- “New EU consortium for new gene therapies EU research project” <https://www.cup.uni-muenchen.de/en/events-and-news/archive/2019/new-eu-consortium-for-new-gene-therapies-eu-research-project/>
- UPGRADE (Unlocking Precision Gene Therapy) – H2020 Project: https://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=7&ved=2ahUKEwiQqrKvi7_mAhWsM-wKHcv0Cp4QFjAGegQIAxAC&url=http%3A%2F%2Fwww.itun.nantes.inserm.fr%2Fcontent%2Fdownload%2F1315%2Ffile%2FH2020%2520UPGRADE.pdf&usg=AOvVaw3N8dA2R4BKoz2ZHI4WEw7
- “Studi in vitro promettenti su terapie che puntano a correggere direttamente il gene (DNA) o il suo messaggero (RNA)”: <https://www.fibrosicistacaricerca.it/domanda-e-risposta/studi-in-vitro-promettenti-su-terapie-che-puntano-a-correggere-direttamente-il-gene-dna-o-il-suo-messaggero-rna/>
- New EU consortium for new gene therapies EU research project: <http://cup.uni-muenchen.de/en/events-and-news/archive/2019/new-eu-consortium-for-new-gene-therapies-eu-research-project/?lang=default>
- New EU consortium for new gene therapies: <https://www.nano-initiative-munich.de/en/press/press-releases/meldung/n/new-eu-consortium-for-new-gene-therapies/>

1.2.5 UPGRADE Promotional Material

The first UPGRADE flyer to present the topic of the project, its objectives and activities of UPGRADE is available (in low and high resolution) at the link <http://www.upgrade-h2020.eu/multimedia/>. A second flyer will present the project achievements at Month 60.

1.2.6 UPGRADE Newsletter

The first issue of the UPGRADE newsletter is planned to be released in late April-early May 2020, right after the first UPGRADE Annual Meeting (already planned for mid-April). It will contain information about the progress of the project (i.e., the outcomes of the Annual Meeting), future events, recent publications and interviews to young scientists involved in the project. The planned structure of the newsletter can be found in the appendix.

2 Dissemination activities

2.1 Participation in scientific events

Event Name	Participant	Title of the presentation	Date dd/mm/yy	Place	Audience	WP(s)
ARVO 2019	TIGEM-Manel Llado	Homology-Independent Targeted Integration in Photoreceptors	01/05/2019	Vancouver	Scientific Community	2,8
ESGCT 2019	TIGEM-Manel Llado	Homology-independent targeted integration to counteract toxic gain-of-functions and loss of transgene expression due to cell proliferation	25/10/2019	Barcelona	Scientific Community	2,8,9
15th Workshop on Novel Technologies and Gene Transfer for Hemophilia	FTELE 1a - Alessio Cantore	Phagocytosis-shielded lentiviral vecors for liver gene therapy of hemophilia B	13/09/2019	Washington	Scientific Community	WP5 - WP9
27th ESGCT / Plenary session	FTELE 1b - Angelo Lombardo	Exploiting Targeted Epigenome Editing for Therapeutic and Biological Applications	23/10/2019	Barcelona	Scientific Community	WP1
27th ESGCT / Plenary session	FTELE 1a - Luigi Naldini	Advanced Genetic Engineering of Hematopoiesis to Treat Inherited Diseases and Cancer	24/10/2019	Barcelona	Scientific Community	WP6
TIDES 2019	LMU Munich, Ernst Wagner	Optimization of novel polymeric delivery vehicles by chemical evolution	20.-23/5/2019	San Diego, USA	Scientific Community	WP4
DPhG	LMU Munich, Ernst Wagner	Therapeutische Nukleinsäuren und Gentherapie: Status und Ausblick	05/06/2019	Munich, Germany	Scientific Community	WP4
DPhG	LMU Munich, Ernst Wagner	Molecular Therapeutics from DNA to Cas9/sgRNA: Chemical Evolution of Nanocarriers	1.-4/9/19	Heidelberg, Germany	Scientific Community	WP4
ICONAN	LMU Munich, Ernst Wagner	Optimizing Nucleic Acid Nanomedicines by Chemical Evolution of Carrier Sequences	17/10/19	Munich, Germany	Scientific Community	WP4

248th ENMC European Neuromuscular Centre (ENMC) International Workshop - Myotonic Dystrophies, Amsterdam (Schiphol)	Invited Speaker : Prof. Dr. Thierry VandenDriessche Vrije Universiteit Brussel	CRISPR/Cas9-based Genome Editing for Myotonic Dystrophy Type 1	11-13/10/19	Amsterdam, The Netherlands	Scientific Community	WP7
27th Annual Congress of the European Society of Gene & Cell Therapy	Invited Speaker : Prof. Dr. Thierry VandenDriessche Vrije Universiteit Brussel	Gene therapy flexes its muscles: Emerging prospects for treating neuromuscular disease.	22-25/10/19	Barcelona, Spain	Scientific Community	WP7
4th Annual Cell and Gene Therapy Symposium	Invited Speaker : Prof. Dr. Thierry VandenDriessche Vrije Universiteit Brussel	Next-generation gene therapy and gene editing for muscle disorders: Duchenne muscular dystrophy and myotonic dystrophy type 1	5- 6 /09/19	Vellore, India	Scientific Community	WP7
San Raffaele Telethon Institute for Gene Therapy	Invited Speaker : Prof. Dr. Thierry VandenDriessche Vrije Universiteit Brussel	Next-generation gene therapy muscle and liver-directed gene therapy	28/01/19	Milan, Italy	Scientific Community	WP7, WP9
Laureate VUB Award Prof. em. Roger Van Geen (Highest scientific distinction of the Free University of Brussels (VUB))	Invited Speaker : Prof. Dr. Thierry VandenDriessche Vrije Universiteit Brussel	Changing the face of modern medicine with gene therapy	10/01/19	Brussels, Belgium	Scientific Community	WP7, WP9
Shake the disease: genomics, genome-scale technology & personalized therapy	Invited Speaker : Prof. Dr. Thierry VandenDriessche Vrije Universiteit Brussel	Gene therapy & gene editing: from trailblazer to game changer	25/04/19	Brussels, Belgium	Scientific Community	WP7, WP9

8th Nijmegen Bleeding symposium	Invited Speaker : Prof. Dr. Thierry VandenDriessche Vrije Universiteit Brussel	Gene therapy for hemophilia: From trailblazer to gamechanger	15/01/19	Nijmegen, The Netherlands	Scientific Community	WP9
34th General Annual Meeting Belgian Hematology Society	Invited Speaker : Prof. Dr. Thierry VandenDriessche Vrije Universiteit Brussel	Gene therapy for hemophilia: From trailblazer to gamechanger	1/02/19	Brussels, Belgium	Scientific Community	WP9
Hämatologie heute,Köln	Invited Speaker : Prof. Dr. Thierry VandenDriessche Vrije Universiteit Brussel	Gentherapie zur Behandlung der Hämophilie	21/03/19	Köln, Germany	Scientific Community	WP9
Wildbad Kreuth Initiative V - Optimal treatment of haemophilia	Invited Speaker : Prof. Dr. Thierry VandenDriessche Vrije Universiteit Brussel	Gene therapy in haemophilia: current status and overview	7-8/06/19	Schloss Hohenkammer, Germany	Scientific Community	WP9
National Hemophilia Foundation Workshop	Invited Speaker : Prof. Dr. Thierry VandenDriessche Vrije Universiteit Brussel	Benefits of optimising vector payloads	13-14/09/19	Washington DC, USA	Scientific Community	WP9
Webinar International Society of Thrombosis & Hemostasis	Invited Speaker : Prof. Dr. Thierry VandenDriessche Vrije Universiteit Brussel	Common concerns in gene therapy	13/10/19	NA	Scientific Community	WP9

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Gene therapy funding solutions, RIZIV/ENAMI	Invited Speaker : Prof. Dr. Thierry VandenDriessche Vrije Universiteit Brussel	Game changing therapies: gene therapy	6/11/19	Brussels, Belgium	Scientific Community	WP9
Nordic Hemophilia Days	Invited Speaker : Prof. Dr. Thierry VandenDriessche Vrije Universiteit Brussel	Update and challenges in gene therapy	21-22/09/19	Malmo, Sweden	Scientific Community	WP9
Medscape - American Society of Hematology meeting	Invited Speaker : Prof. Dr. Thierry VandenDriessche Vrije Universiteit Brussel	The science of gene therapy	6/12/19	Orlando, Florida, USA	Scientific Community	WP9

2.2 Scientific publications

In the first year, three scientific papers have been published by the UPGRADE research partners:

1. Peng, L. and E. Wagner (2019). "Polymeric Carriers for Nucleic Acid Delivery: Current Designs and Future Directions." Biomacromolecules **20**(10): 3613-3626.
2. Lansing, F., et al. (2019). "A heterodimer of evolved designer-recombinases precisely excises a human genomic DNA locus." Nucleic acids research.
3. Perdiguero, E., et al. (2019). "Simultaneous Isolation of Stem and Niche Cells of Skeletal Muscle: Applicability for Aging Studies."

List of annexes

Annex 1 – Layout and structure of the UPGRADE Newsletter

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