



***ProteoCURE and
patient associations:
Joining efforts***

ACTIVITIES & HIGHLIGHTS

by the ProteoCURE dissemination committee

ProteoCURE success relies in our capacity to integrate all different sectors participating in our action: fundamental and clinically oriented research scientists, industrial partners and patient associations. In this issue we focus on the interaction with patient association and you will find herein some interviews with Roberto Pugliese from Glioblastoma Italy, Bruna Scaggiante from the Italian League for the Fight against Tumours and Alessandra Ferletti from the Unione Italiana Lotta alla distrofia muscolare to whom we asked: i) how do they work? ii) What do they need from us? iii) How can we improve our interactions with them.

Of course, we also need to improve our interactions with other sectors and for this reason the organizing committee of the next ProteoCURE annual meeting is considering sessions in which we invite representatives of all sectors including industry and clinicians to meet them and ameliorate the way we are working with them. We are also working in the implementation of measures to increase the impact of our action at all levels.

The Core Group and all committee representatives met in Paris on October 12, 2023 to discuss different initiatives to implement in order to improve the communication, dissemination, implication of all sectors, support to young investigators to attend our meetings and to benefit from short-term scientific missions. For all those reasons, you should not miss our next annual meeting in Warsaw.

PAST SCIENTIFIC EVENTS

EMBO Workshop “SUMOylation; from discovery to translation”, co-organized by ProteoCure

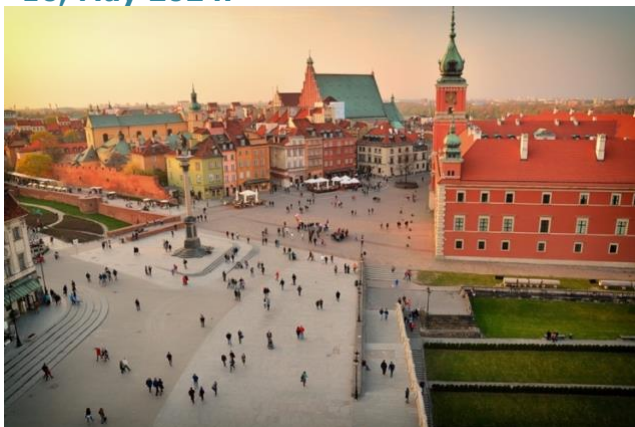


125 scientists came together at the Atlantic coast in Póvoa de Varzim, Portugal on 25-28 September 2023, to discuss the vibrant field of Small Ubiquitin-like Modifiers. Topics covered included: SUMO machinery and mechanisms, SUMO condensate dynamics, transcription, chromatin dynamics and cell fate identity, immunity, infection and senescence, genotoxic stress response and genome stability, proteotoxic stress response and proteome stability as well as targeting and exploiting SUMO networks in cancer and beyond. High points included two spirited poster sessions, excellent student and early career researcher talks and inspirational keynotes from Anne Dejean (Institut Pasteur), Hugues de Thé (Collège de France), Ronald Hay (University of Dundee) and Michael Matunis (Johns Hopkins University). Overall, the meeting was notable for the outstanding networking opportunities, exciting science and a strong sense of community.

ABOUT OUR COMING SCIENTIFIC EVENTS

ProteCURE ANNUAL MEETING 2024: FIRST ANNOUNCEMENT

The 3rd PROTEOCURE Annual Meeting will take place in Warsaw, Poland. 7-10, May 2024.



Registration and abstract submission will be available from January 2024 until the end of March 2024.

More information you will find soon on our conference website: <https://proteocure2024.sciencesconf.org>

Please forward this information to students and postdocs in your lab!

We encourage young scientists to participate:

Slots for short talks are available and will be selected from submitted abstracts; present your research as a poster; Gain experience as session chair; Travel support will be available.

Organising Committee: Oliver Coux (ProteoCure Chair), Rosa Farras (ProteoCure Vice-Chair), Christine Blattner, Efthimios Skoulakis, Justyna McIntyre (Local Organizer), Ulrike Topf (Local Organizer), Laetitia Poidevin (ProteoCure Project Manager).

Venue: Hotel Mercure Warszawa Grand <https://all.accor.com/hotel/3384/index.en.shtml>

The link to the meeting website is: <https://proteocure.eu/annual-meeting-2024/>



Founded by the European Union

COST (European Cooperation in Science and Technology) is a funding agency for research and innovation networks. Our Actions help connect research initiatives across Europe and enable scientists to grow their ideas by sharing them with their peers. This boosts their research, career and innovation.

INTERVIEWS WITH PATIENT ASSOCIATIONS

Last spring, we had the opportunity to meet and interview in Trieste representatives of several patient associations. In this picture, from right to left Roberto Pugliese from Glioblastoma.IT, Bruna Scaggiante from the Italian League for the Fight against Tumors, Alberto Tomassini from Associazione Azurra and Alessandra Ferletti from the Unione Italiana Lotta alla distrofia muscolare. We aimed to better understand their mission and the way they work in order to better collaborate with them in the future.



Glioblastoma.IT ODV

Who are you? I am Roberto Pugliese and I am Computer Scientist with an MBA and a PhD in Management. Currently, I am Deputy General Coordinator at Elettra Sincrotrone, Director of the IT Division and responsible for digital transition. An expert in the fields of data science, artificial intelligence, robotics, innovation management, business models and start-up growth, since 2018 I have been an Ambassador of Singularity University, a prestigious educational institute focused on innovation and advanced technology, founding the Trieste Chapter. In 2018, I lost my 20-year-old son Emanuele from glioblastoma.

What is Glioblastoma.IT ODV? It was launched in 2019 and since 2021 has become Glioblastoma.IT ODV, a volunteer organisation committed to spreading information and awareness on brain tumours, promoting research and helping patients to get the best available treatment options. Glioblastoma.IT ODV supports patients and caregivers with an eye to the panorama of international research and the aim of being of help by providing updated information on therapies and specialized centers for the treatment of glioblastoma and by putting patients and caregivers in contact with high profile professionals. The funds we raise are intended to maintain our services and support patients who wish to try second-line therapies.

Italian League for the Fight against Tumors (LILT)

Who are you? I am Bruna Scaggiante and I am a PhD researcher and professor in molecular biology of the University of Trieste. I am working on biomarkers for tumors in cells, liquid biopsies and antineoplastic therapies with nucleic acid-based drugs. I am a member of the EACR and guest editor of international peer-reviewed journals. I have been active in the field of bioethics since 2013. I led the Association Lega Italiana per la Lotta contro I Tumori (LILT) of Trieste, working on cancer prevention and social sustainability. In December 2019, I was awarded the title of Knight of the Order of Merit of the Italian Republic. Currently, I am coordinator of LILT Friuli Venezia Giulia and member of the Scientific and Technical Committee for LILT, Public Body.

What is LILT ? LILT is the only public institution founded on an association basis and awarded the Gold Medal for services to public health. It has been operating for more than 100 years (1922) as a non-profit organization throughout the national territory, to fight cancer by promoting prevention. It is composed of 106 provincial associations that are autonomous entities but pursue the LILT goals. It is under the high patronage of the President of the Italian Republic and is subject to the direct supervision of the Ministry of Health as well as the Ministry of Economy and Finance and the control of the Court of Auditors. It collaborates with the State, Regions, Provinces and Municipalities, as well as with national and international oncology organizations. LILT is mainly aims at 1) **Primary prevention** (education on healthy lifestyles and environmental and occupational carcinogenesis); 2) **Secondary prevention** (promoting early cancer detection and diagnosis); 3) **Tertiary prevention** (patient care, promotion of rehabilitation, and support for families and caregivers); and 4) **Scientific research** (funding research on the 3 above-mentioned items). LILT also drives national campaigns such as National Oncology Prevention Week ; No Smoking Day; Skin Tumors Prevention Week ; LILT for women (October); LILT for men (November).

To get support, researchers can contact the association to participate in a **research program to be partially funded or to start a crowdfunding effort**. In addition, the association may sponsor a **researcher's scholarship or doctorate**. For this purpose, the association and the researcher must meet to pursue common goals and efforts and consider the possible application of the results. **Understanding disease development and progression, as well as identifying novel biomarkers and therapeutic targets is crucial to find new solutions**. In addition, an effective communication is needed to raise **awareness on the importance of basic research** that is not directly related to biomedical applications.

Unione Italiana Lotta alla distrofia muscolare (UILDM)

Who are you? My name is Alessandra Ferletti, and I am 48 years old, and I am President of UILDM Gorizia Section. I suffer from SMA2. When I first started experiencing symptoms of the disease a few months after birth, specialists informed my parents that I likely had a form of spinal amyotrophy. They explained that if I surpassed the first year and a half of life, it meant I didn't have the most severe form of the disease. You can imagine the psychological state of my family and their anxiety throughout my journey. Nowadays, a simple blood test can immediately determine if it is type 1, 2, 3, or 4, allowing for appropriate therapy to alleviate or even eliminate the consequences of the disease. Neonatal screening enables immediate treatment, enabling children to live without the burden of illness. The progress made in this field has been astonishing, and it's all thanks to researchers like you!

What is Unione Italiana Lotta alla distrofia muscolare? UILDM is the major Italian muscular dystrophy association. It was founded in 1961 in Trieste by Federico Milcovich, a man with muscular dystrophy who realized the strength in unity. UILDM is an umbrella association that takes care of the daily needs of people with various neuromuscular diseases. We have 66 sections spread across the country, including our section serving the Gorizia and Trieste area.

UILDM association supports scientific research and development related to muscular dystrophies and other neuromuscular diseases, while also promoting social inclusion for people with disabilities. Over the years, we have responded to real and concrete needs through various initiatives and projects, such as sports events, psychological support, art in schools, transportation services, rehabilitation therapies, and overall enhancements to quality of life. UILDM also supports clinical research through Fondazione Telethon, a funding agency dedicated to research on muscular dystrophies and other genetic diseases. Our goal is to provide individuals with the freedom to live just like anyone else. In the last decade, UILDM and Telethon have made significant progresses by i) **establishing an Italian clinical network** dedicated to researching the quality of life of people living with neuromuscular diseases and ii) **creating the NEMO clinical centers (multidisciplinary approach)**, which follow a patient-centered model and adopt a holistic approach to clinical care and research.

UILDM would like to stress the importance of focusing not only on a **definitive cure, but also on treatments which could relieve symptoms, slow down the progression of the disease and improve the quality of life of patients in the short term**. Furthermore, we think that a **better exchange of information and more cooperation between researchers and patients' associations** is of vital importance to better understand the daily experiences of our stakeholders and their specific needs. The latter could be achieved through conferences (bilateral), seminars (bilateral) as well as newsletters and online updates. Finally, we would like to underline the importance of HOPE. Every step forward and every new treatment gives hope to our members and hope, too, improves their quality of life.

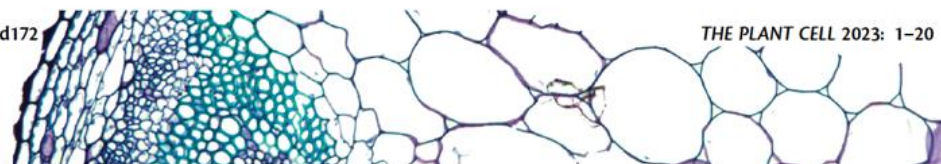
if you have **any publication or information about clinical trials for glioblastoma/cancer/muscular dystrophy or if there is any information we can disseminate to help patients or specialists** let us know at:

<https://www.linkedin.com/in/robypugliese/> ; <https://twitter.com/robypugliese> ;
<https://www.facebook.com/robypugliese/>; www.lilt.it ; <https://www.uildm.org/>

We, ProteoCURE members sincerely thank very much the contribution of these associations to this special issue.

<https://doi.org/10.1093/plcell/koad172>

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THE PLANT CELL 2023: 1–20

Research Article

Arabidopsis metacaspase MC1 localizes in stress granules, clears protein aggregates, and delays senescence

Nerea Ruiz-Solaní ^{1,2} Jose Salguero-Linares ^{1,†} Laia Armengot ^{1,2} Jaime Santos ³
Irantzu Pallarès ³ Katarina P. van Midden ⁴ Ujjal J. Phukkan ^{1,†} Seda Koyuncu ⁵
Júlia Borràs-Bisa ¹ Liang Li ¹ Crina Popa ¹ Frederik Eisele ⁶ Anna Maria Eisele-Bürger ⁶
Sandra Malgrem Hill ⁶ Emilio Gutiérrez-Beltrán ^{7,8} Thomas Nyström ⁶ Marc Valls ^{1,2}
Ernesto Llamas ⁹ David Vilchez ^{5,10,11} Marina Klemenčič ⁴ Salvador Ventura ³ and
Nuria S. Coll ^{1,12,*}

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