



## Curriculum Vitae

### Personal information **Federica Chiara**

#### Work experience

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1. Employer: University of Padova
  - Start date: 102007
  - End date:
  - Position: Assistant Professor
  - Activities: Oncology Research, Rare Disease research Carcinogenesis Teaching activity: Toxicology, Carcinogenic Risk assessment, Sustainable Ecology
  - Country: Italy
2. Employer: Linfa Association
  - Start date: 052019
  - End date:
  - Position: President
  - Activities: Project management of projects aimed to increase patient knowledge, awareness, and well\_being.
  - Country: Italy

#### Education and training

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1. Subject: Conservatorio di Musica G. Verdi
  - Start date: 091989
  - End date: 081994
  - Qualification: Degree (Diploma)
  - Organisation: Piano Player
  - Country: Italy
2. Subject: University of Turin
  - Start date: 091994
  - End date: 101996
  - Qualification: Degree
  - Organisation: Biology
  - Country: Italy
3. Subject: University of Turin
  - Start date: 021997
  - End date: 052000
  - Qualification: PhD
  - Organisation: Molecular Oncology
  - Country: Italy
4. Subject: Ludwig Institute for cancer research
  - Start date: 022002
  - End date: 022004
  - Qualification: Post doc fellow
  - Organisation: Basic research in Oncology. Proteomic
  - Country: Sweden
5. Subject: S. Luigi Gonzaga Hospital, Cavallieri Ottolenghi
  - Start date: 032004
  - End date: 012006
  - Qualification: Junior Group Leader
  - Organisation: Molecular mechanisms of Neuronal Senescence. Proteomic, Molecular Oncology, and toxicology
  - Country: Italy
6. Subject: University of Padova
  - Start date: 012007
  - End date: 082008
  - Qualification: Research Grant
  - Organisation: Mitochondria function and drug toxicity
  - Country: Italy

#### Additional information

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##### Publications

1 2021 Ciscato, Francesco, Chiara, Federica, Filadi, Riccardo, Rasola, Andrea (2021). Analysis of the Effects of Hexokinase 2 Detachment From Mitochondria\_Associated Membranes with the Highly Selective Peptide HK2pep. *BIO\_PROTOCOL*, vol. 11, ISSN: 2331\_8325, doi: 10.21769/BioProtoc.4087 2 2021 Chiara, Federica, Indraccolo, Stefano, Trevisan, Andrea (2021). Filling the gap between risk assessment and molecular determinants of tumor onset. *CARCINOGENESIS*, vol. 42, p. 507\_516, ISSN: 0143\_3334, doi: 10.1093/carcin/bgaa135 3 2021 Errico A., Stocco A., Riccardi V. M., Gambalunga A., Bassetto F., Grigatti M., Ferlosio A., Tadini G., Ferraresi S., Trevisan A., Giustini S., Rasola A., Chiara F. (2021). Neurofibromin deficiency and extracellular matrix cooperate to increase transforming potential through fak\_dependent signaling. *CANCERS*, vol. 13, 2329, ISSN: 2072\_6694, doi: 10.3390/cancers13102329 4 2020 Ciscato, Francesco, Filadi, Riccardo, Masgras, Ionica, Pizzi, Marco, Marin, Oriano, Damiano, Nunzio, Pizzo, Paola, Gori, Alessandro, Frezzato, Federica, Chiara, Federica, Trentin, Livio, Bernardi, Paolo, Rasola, Andrea (2020). Hexokinase 2 displacement from mitochondria - associated membranes prompts Ca<sup>2+</sup> - dependent death of cancer cells. *EMBO REPORTS*, ISSN: 1469\_221X, doi: 10.15252/embr.201949117 5 2019 Pettenuzzo N, Brustolin L, COLTRI, ELISA, Gambalunga A, Chiara F, Trevisan A, Biondi B, Nardon C, Fregona D. (2019). Cull and Aull Complexes

with Glycoconjugated Dithiocarbamate Ligands for Potential Applications in Targeted Chemotherapy.. CHEMMEDCHEM, vol. 14, p. 1162\_1172, ISSN: 1860\_7179, doi: 10.1002/cmcd.201900226 6 2018 Brustolin, L., Nardon, C., Pettenuzzo, N., Zuin Fantoni, N., Quarta, S., Chiara, F., Gambalunga, A., Trevisan, A., Marchiò, L., Pontisso, P., Fregona, D. (2018). Synthesis, chemical characterization and cancer cell growth\_inhibitory activities of Cu(II) and Ru(III) aliphatic and aromatic dithiocarbamate complexes. DALTON TRANSACTIONS, vol. 47, p. 15477\_15486, ISSN: 1477\_9226, doi: 10.1039/c8dt02965b 7 2017 MASGRAS, IONICA, CISCATO, FRANCESCO, BRUNATI, ANNA MARIA, TIBALDI, ELENA, INDRACCOLO, STEFANO, CURTARELLO, MATTEO, CHIARA, FEDERICA, CANNINO, GIUSEPPE, Papaleo, Elena, Lambrugh, Matteo, Guzzo, Giulia, GAMBALUNGA, ALBERTO, PIZZI, MARCO, GUZZARDO, VINCENZA, RUGGE, MASSIMO, VULJAN, STEFANIA EDITH, CALABRESE, FIORELLA, BERNARDI, PAOLO, RASOLA, ANDREA (2017). Absence of Neurofibromin Induces an Oncogenic Metabolic Switch via Mitochondrial ERK\_Mediated Phosphorylation of the Chaperone TRAP1. CELL REPORTS, vol. 18, p. 659\_672, ISSN: 2211\_1247, doi: 10.1016/j.celrep.2016.12.056 8 2017 BORELLA VENTURINI, MATTEO, FRASSON, CLARA, PALUAN, FILIPPO, DE NUZZO, DAVIDE, DI MASI, GIACOMO, GIRALDO, MONICA, CHIARA, FEDERICA, TREVISAN, ANDREA (2017). Tetanus vaccination, antibody persistence and decennial booster: a serosurvey of university students and at\_risk workers. EPIDEMIOLOGY AND INFECTION, vol. 145, p. 1757\_1762, ISSN: 0950\_2688, doi: 10.1017/S0950268817000516 9 2017 Borella\_venturini Matteo, Frasson Clara, PALUAN, FILIPPO, DE NUZZO, DAVIDE, DI MASI, GIACOMO, Giraldo Monica, Chiara Federica, Trevisan Andrea (2017). Tetanus vaccination, antibody persistence and decennial booster; Reply to 'New guidelines about tetanus vaccination schedules in Europe should be evaluated with caution' by Eldin and co\_workers.. EPIDEMIOLOGY AND INFECTION, vol. 145, p. 2777\_2778, ISSN: 0950\_2688, doi: 10.1017/S0950268817001741 10 2016 SCINTILLA, SIMONE, BRUSTOLIN, LEONARDO, GAMBALUNGA, ALBERTO, CHIARA, FEDERICA, TREVISAN, ANDREA, NARDON, CHIARA, FREGONA, DOLORES (2016). Ru(III) anticancer agents with aromatic and non\_aromatic dithiocarbamates as ligands: Loading into nanocarriers and preliminary biological studies. JOURNAL OF INORGANIC BIOCHEMISTRY, vol. 165, p. 159\_169, ISSN: 0162\_0134, doi: 10.1016/j.jinorgbio.2016.11.018 11 2015 NARDON, CHIARA, CHIARA, FEDERICA, BRUSTOLIN, LEONARDO, GAMBALUNGA, ALBERTO, CISCATO, FRANCESCO, RASOLA, ANDREA, TREVISAN, ANDREA, FREGONA, DOLORES (2015). Gold(III)\_pyrrolidinedithiocarbamate Derivatives as Antineoplastic Agents. CHEMISTRYOPEN, vol. 4, p. 183\_191, ISSN: 2191\_1363, doi: 10.1002/open.201402091 12 2015 TREVISAN, ANDREA, NICOLLI, ANNAMARIA, CHIARA, FEDERICA (2015). Hepatitis B: prevention, protection, and occupational risk.. FUTURE VIROLOGY, vol. 10, p. 53\_61, ISSN: 1746\_0794, doi: 10.2217/FVL.14.90 13 2015 TREVISAN, ANDREA, MORANDIN, MARTA, FRASSON, CLARA, Pantaleoni, A, DONAZZAN, ARIANNA, BALLARIN, DEBORA, NICOLLI, ANNAMARIA, BARTOLUCCI, GIOVANNI BATTISTA, CHIARA, FEDERICA (2015). Prevalence of measles virus\_specific IgG antibodies according to vaccination schedule in medical students of Padua University.. FUTURE VIROLOGY, vol. 7, p. 817\_826, ISSN: 1746\_0794, doi: 10.2217/FVL.15.50 14 2014 NICOLLI, ANNAMARIA, Bisinella G, Padovani G, Vitella A, CHIARA, FEDERICA, TREVISAN, ANDREA (2014). Predictivity and fate of metal ion release from metal\_on\_metal total hip prostheses.. THE JOURNAL OF ARTHROPLASTY, vol. 29, p. 1763\_1767, ISSN: 0883\_5403, doi: 10.1016/j.arth.2014.04.041 15 2014 NICOLLI, ANNAMARIA, CHIARA, FEDERICA, GAMBALUNGA, ALBERTO, CARRIERI, MARIELLA, BARTOLUCCI, GIOVANNI BATTISTA, TREVISAN, ANDREA (2014). Reliability of urinary excretion rate adjustment in measurements of urinary hippuric acid.. INTERNATIONAL JOURNAL OF ENVIRONMENTAL RESEARCH AND PUBLIC HEALTH, vol. 11, p. 7036\_7044, ISSN: 1661\_7827, doi: 10.3390/ijerph110x0000x 16 2013 CHIARA, FEDERICA, RASOLA, ANDREA (2013). GSK\_3 and mitochondria in cancer cells. FRONTIERS IN ONCOLOGY, vol. 3, p. 1\_6, ISSN: 2234\_943X, doi: 10.3389/fonc.2013.00016 17 2013 CHIARA, FEDERICA, BARTOLUCCI, GIOVANNI BATTISTA, Mongillo M, Ferretto L, NICOLLI, ANNAMARIA, TREVISAN, ANDREA (2013). Hepatitis B vaccination at three months of age: a successful strategy?. VACCINE, vol. 31, p. 1696\_1700, ISSN: 0264\_410X, doi: 10.1016/j.vaccine.2013.01.046 18 2013 CHIARA, FEDERICA, BARTOLUCCI, GIOVANNI BATTISTA, CATTAL, MARGHERITA, Piazza A, NICOLLI, ANNAMARIA, BUJA, ALESSANDRA, TREVISAN, ANDREA (2013). Hepatitis B vaccination of adolescents: significance of non\_protective antibodies.. VACCINE, vol. 32, p. 62\_68, ISSN: 0264\_410X, doi: 10.1016/j.vaccine.2013.10.074 19 2013 Cristofori P, Defazio R, Chiusolo A, MONGILLO, MICHELE, BARTOLUCCI, GIOVANNI BATTISTA, CHIARA, FEDERICA, TREVISAN, ANDREA (2013). Hyaline droplet accumulation in kidney of rats treated with hexachloro\_1:3\_butadiene: influence of age, dose, and time\_course. JOURNAL OF APPLIED TOXICOLOGY, vol. 33, p. 183\_189, ISSN: 0260\_437X, doi: 10.1002/jat.1732 20 2012 CHIARA, FEDERICA, GAMBALUNGA, ALBERTO, SCIACOVELLI, MARCO, A. Nicolli, RONCONI, LUCA, FREGONA, DOLORES, BERNARDI, PAOLO, RASOLA, ANDREA, TREVISAN, ANDREA (2012). Chemotherapeutic induction of mitochondrial oxidative stress activates GSK\_3 $\alpha$ / $\beta$  and Bax, leading to permeability transition pore opening and tumor cell death. CELL DEATH & DISEASE, vol. 3, ISSN: 2041\_4889, doi: 10.1038/cddis.2012.184 21 2012 TREVISAN, ANDREA, CHIARA, FEDERICA, MONGILLO, MICHELE, QUINTIERI, LUIGI, Cristofori P. (2012). Sex\_related differences in renal toxicodynamics in rodents. EXPERT OPINION ON DRUG METABOLISM & TOXICOLOGY, vol. 8, p. 1173\_1188, ISSN: 1742\_5255, doi: 10.1517/17425255.2012.698262 22 2011 JAMBEKAR AA, PALMA, ELENA, NICOLOSI L, RASOLA, ANDREA, PETRONILLI V, CHIARA, FEDERICA, BERNARDI, PAOLO, NEEDLEMAN R, BRUSILOV WSA (2011). A Glutamine Synthetase inhibitor increases survival and decreases cytokine response in a mouse model of Acute Liver Failure. LIVER INTERNATIONAL, vol. 31, p. 1209\_1221, ISSN: 1478\_3223, doi: 10.1111/j.1478\_3231.2011.02553.x 23 2011 Martin MG, Trovo L, Perga S, Sadowska A, RASOLA, ANDREA, CHIARA, FEDERICA, Dotti CG (2011). Cyp46 mediated cholesterol loss promotes survival in stressed hippocampal neurons. NEUROBIOLOGY OF AGING, vol. 32, p. 933\_943, ISSN: 0197\_4580, doi: 10.1016/j.neurobiolaging.2009.04.022 24 2011 LEMBO FAZIO L, NIGRO G, NOEL G, ROSSI G, CHIARA, FEDERICA, TSILINGIRI K, RESCIGNO M, RASOLA, ANDREA, BERNARDINI ML (2011). Gadd45 $\alpha$  activity is the principal effector of Shigella mitochondria\_dependent epithelial cell death in vitro and ex vivo.. CELL DEATH & DISEASE, vol. 2, ISSN: 2041\_4889, doi: 10.1038/cddis.2011.4 25 2011 Marzano, Cristina, Ronconi, Luca, Chiara, Federica, Giron, Maria Cecilia, Faustinielli, Ivo, Cristofori, Patrizia, Trevisan, Andrea, Fregona, Dolores (2011). Gold(III)\_dithiocarbamate anticancer agents: activity, toxicology and histopathological studies in rodents. INTERNATIONAL JOURNAL OF CANCER, vol. 129, p. 487\_496, ISSN: 0020\_7136, doi: 10.1002/ijc.25684 26 2011 NICOLLI, ANNAMARIA, CHIARA, FEDERICA, Bortoletti I, PASQUALATO, FABIOLA, MONGILLO, MICHELE, GAMBALUNGA, ALBERTO, Biggi F, TREVISAN, ANDREA (2011). Rilascio di metalli da protesi d'anca metallo-su\_metallo. GIORNALE ITALIANO DI MEDICINA DEL LAVORO ED ERGONOMIA, vol. 33 (suppl), p. 257\_259, ISSN: 1592\_7830 27 2011 MASO, STEFANO, NICOLLI, ANNAMARIA, GAMBALUNGA, ALBERTO, MONGILLO, MICHELE, CHIARA, FEDERICA, TREVISAN, ANDREA (2011). Testosterone and estradiol affect renal oxidative metabolism and glutathione pathway of Wistar rats. JOURNAL OF DRUG METABOLISM & TOXICOLOGY, vol. S7, ISSN: 2157\_7609, doi: 10.4172/2157\_7609 28 2010 RASOLA, ANDREA, SCIACOVELLI, MARCO, CHIARA, FEDERICA, PANTIC, BORIS, BRUSILOV WS, BERNARDI, PAOLO (2010). Activation of mitochondrial ERK protects cancer cells from death through inhibition of the permeability transition. PROCEEDINGS OF THE NATIONAL ACADEMY OF SCIENCES OF THE UNITED STATES OF AMERICA, vol. 107, p. 726\_731, ISSN: 0027\_8424, doi: 10.1073/pnas.0912742107 29 2010 TREVISAN, ANDREA, NICOLLI, ANNAMARIA, CHIARA, FEDERICA (2010). Are rats the appropriate experimental model to understand age\_related renal drug metabolism and toxicity?. EXPERT OPINION ON DRUG METABOLISM & TOXICOLOGY, vol. 6, p. 1451\_1459, ISSN: 1742\_5255, doi: 10.1517/17425255.2010.531701 30 2010 ZANETTI, EDOARDO, CHIUSOLO A, DEFAZIO R, CASARTELLI A, CAPPELLETTI E, BOCCHINI N, CHIARA, FEDERICA, CRISTOFORI P, TREVISAN, ANDREA (2010). Evaluation of aging influence on renal toxicity caused by segment\_specific nephrotoxics of the proximal tubule in rat. JOURNAL OF APPLIED TOXICOLOGY, vol. 30, p. 142\_150, ISSN: 0260\_437X, doi: 10.1002/jat.1480 31 2010 MONGILLO, MICHELE, CHIARA, FEDERICA, RANZATO, MADDALENA, TREVISAN, ANDREA (2010). Strategy for hepatitis A seroprevalence survey in a population of young people. VACCINE, vol. 28, p. 6985\_6988, ISSN: 0264\_410X, doi: 10.1016/j.vaccine.2010.08.044 32 2008 Martin MG, Perga S, Trovo L, RASOLA, ANDREA, Holm P, Rantamäki T, Harkany T, Castrén E, CHIARA, FEDERICA, Dotti CG (2008). Cholesterol loss enhances TrkB signaling in hippocampal neurons aging in vitro. MOLECULAR BIOLOGY OF THE CELL, vol. 19, p. 2101\_2112, ISSN: 1059\_1524, doi: 10.1091/mbc.E07\_09\_0897 33 2008 CHIARA, FEDERICA, CASTELLARO D, MARIN, ORIANO, PETRONILLI V, BRUSILOV WS, JUHASZOVA M, SOLLOTT SJ, FORTE M, BERNARDI, PAOLO, RASOLA, ANDREA (2008). Hexokinase II detachment from mitochondria triggers apoptosis through the permeability transition pore independent of voltage\_dependent anion channels. PLOS ONE, vol. 3, ISSN: 1932\_6203, doi: 10.1371/journal.pone.0001852 34

2004 CHIARA, FEDERICA, GOUMANS MJ, FORSBERG H, AHGREN A, RASOLA, ANDREA, ASPENSTROM P, WERNSTEDT C, HELLBERG C, HELDIN CH, HEUCHEL R. (2004). A gain of function mutation in the activation loop of platelet-derived growth factor beta\_receptor deregulates its kinase activity. THE JOURNAL OF BIOLOGICAL CHEMISTRY, vol. 279, p. 42516\_42527, ISSN: 0021\_9258, doi: 10.1074/jbc.M406051200 35 2004 CHIARA, FEDERICA, BISHAYEE S, HELDIN CH, DEMOULIN JB (2004). Autoinhibition of the platelet-derived growth factor beta\_receptor tyrosine kinase by its C-terminal tail. THE JOURNAL OF BIOLOGICAL CHEMISTRY, vol. 279, p. 19732\_19738, ISSN: 0021\_9258 36 2003 CHIARA, FEDERICA, MICHELI P, PUGLIESE L, COMOGLIO PM (2003). Mutations in the met oncogene unveil a "dual switch" mechanism controlling tyrosine kinase activity. THE JOURNAL OF BIOLOGICAL CHEMISTRY, vol. 278, p. 29352\_29358, ISSN: 0021\_9258, doi: 10.1074/jbc.M302404200

## Projects

Scientific Research: Project lines at the Institute for Cancer Research and Treatment (IRCCS) in Candiolo (Turin) directed by Prof. Comoglio: 1) Inhibition of the activity of the Met proto-oncogene by recombinant single-chain antibodies engineered from monoclonal antibodies directed against critical domains of the enzyme. By means of a lentiviral vector system, an attempt was made to have the single-chain construct expressed by the cells themselves so as to block activity directly from within the cell by acting on the cytoplasmic kinase site of the protein. 2) Analysis of the molecular determinants responsible for neoplastic transformation in the MET receptor. The enzyme tyrosine kinase MET has been observed to be constitutively active in many carcinomas. This deregulated activity is at the basis of the aetiology of these tumours. In Prof. Comoglio's group, a regulatory mechanism of intracellular self-inhibition has been shown for the first time to be released at a physiological level only following activation mediated by ligand binding. The insertion of point mutations identified in samples from patients with renal papillary carcinoma and gastric carcinoma into the active site revealed the mechanisms of mutation-mediated removal of allosteric inhibition with subsequent activation of the receptor even in the absence of ligand. Project line at the Ludwig Institute directed by Prof. Carl-Henrik Heldin 3) Study of the intramolecular mechanisms regulating the kinase activity of the PDGF-Beta receptor. In this study, two novel auto-inhibitory mechanisms in the PDGF-Beta receptor were revealed: the first maintains the activation site in a 'closed' conformation, the second auto-inhibitory mechanism involves the C-terminal tail of PDGF-Beta. Both are unlocked physiologically by ligand binding, and pathologically by the same point mutations found in tumours. The steric alteration resulting from the introduction of point mutations detected in tumours also significantly alters the interaction with proteins downstream of the receptor, favouring the activation of the products of oncogenes such as Akt and Ras. Projects at the laboratory directed by Prof. Dotti (Turin, S. Luigi Gonzaga hospital, and Lovaglio, Bergamo): 4) Study on the molecular mechanisms involved in the senescence of hippocampal neurons. The group showed that during senescence neurons resist death stimuli by activating the growth factor receptor NGF and BDNF belonging to the Trk family, which regulates survival in a ligand-independent manner. This activation is induced by a regulated loss of membrane cholesterol, which changes the structure of membrane platforms or Membrane Rafts, favouring the segregation and activation of Trk in these lipid platforms. The study uncovered the molecular mechanisms behind the decline in membrane cholesterol levels and the toxic stimulus that triggers them. In addition, the molecular cascade downstream of the Trk receptor, which is activated to ensure neuronal survival even in the absence of growth factors as occurs during senescence, was also elucidated. Project at the laboratory directed by Prof. Paolo Bernardi of Padua (Department of Biomedical Sciences): 5) Study of the influence of some tyrosine kinases on the activity of the mitochondrial permeability pore (PTP) in tumour models. We investigated the molecular mechanisms by which key kinases in the control of cell survival and metabolism confer to neoplastic cells an increased resistance to intrinsic apoptotic death. We found that these kinases directly regulate PTP opening and that their constitutive activation, frequent in many tumours, causes PTP desensitisation to open even under conditions of oxidative stress or lack of growth factors typical of the environment in which tumour cells are able to proliferate. Project line at the laboratory carried out with own funds in collaboration with other groups: 6) Study of muramylpeptide-mediated toxicity on colon epithelial cells. In collaboration with the group directed by Prof. Lisa Bernardini of Rome, the pro-apoptotic mechanism triggered by the incorporation of muramylpeptides secreted by the bacterium Shigella into epithelial cells was highlighted. The work is innovative as it highlights that infection causes intrinsic apoptotic death through mitochondrial depolarization. In addition, the cellular response mechanism to stress represented by the cell cycle arrest following DNA damage has been identified through the involvement of molecules hitherto considered extraneous to the apoptotic death process. 7) Study of the cytotoxicity and molecular mechanisms of recently formulated gold-based chemotherapy molecules (AuIII). The Department of Inorganic Chemistry has designed and produced a panel of gold-based molecules as potential antitumour drugs. Preliminary experiments revealed that the molecules have the ability to reverse solid tumours such as those of the prostate in vivo while maintaining low toxicity. The Industrial Toxicology group studied the mechanisms of action of these molecules, highlighting an interesting pro-oxidative activity of mitochondrial origin due to the inhibition of one of the respiratory chain complexes. This inhibition leads to increased production of oxygen radicals which, by pathologically activating some tyrosine kinase enzymes, sensitize the mitochondrial permeability pore (PTP) to opening and thus to the apoptotic death of the cancer cells. Considering that PTP is desensitized in many solid tumours, the gold molecules have been shown to be selective towards cancer cells. 8) Study of the mechanisms underlying the onset and progression towards malignancy of neurofibromas, benign tumours that arise in patients with type 1 neurofibromatosis genetic syndrome (incidence 1/3000). In particular, the group focused on the influence of the microenvironment in the progression of the benign lesion towards malignancy. In vitro multicellular models useful for the study and screening of drugs have been developed. In parallel with the Pathological Anatomy directed by Prof. Angelo Paolo Dei Tos and other centers in Milan and Bologna are defining a panel of early indicators of malignancy. Linfa Association Projects: \_SUPPORTING SCIENTIFIC RESEARCH ON THE NEUROFIBROMATOSIS. In the last 5 years Linfa has been financing two research projects on NF and a grant, all selected by a scientific committee of four Italian scientists, expert in the NF1/NF2 and cancer fields. The titles of the ongoing projects are "Una sfida per la vita" and "Togliamo energia al tumore" (Eng. Transl. A challenge for life; We take the power out of the tumor). Linfa OdV is also financing a fellowship to a clinician in the project "Il futuro negli occhi" (Eng. Transl. "The future in your eyes") at the University of Padova. Also see [<https://www.linfaeurofibromatosi.com/>] \_ PROVIDING A SUPPORT to patients and their families through psychological services, orientation to the most qualified medical center for NF in order to higher their quality of life. Linfa is providing an economical support to the families of NF children dealing with neurodevelopmental disorders. These individuals need to afford expensive therapies such as speech therapy and others. The title of this project is "Diamo la parola ai bambini" (Eng. Transl. "Let the children speak"). Then, we have a psychological support for parents in the first period after the diagnosis of NF; the project name is "Mamme di rara Bellezza" (translation: Mom's of rare beauty). Linfa also provides a direct phone line "Pronto Linfa" (Eng. Transl. "Call for Linfa") for information and patients' personal support. \_RISING AWARENESS, INFORMATION, EDUCATION on neurofibromatosis. Linfa pursues the idea that individuals suffering from a rare disease have the right to know more about their disease. This can enable them to understand the medical and scientific language, thus to understand and share the therapeutic choices proposed to them and to increase therapeutic adherence. In order to enhance knowledge, appropriate communication strategies are developed, such as booklets, articles, videos in a language understood by all, but rich in depth content. Conferences and events (like Eurordis Rare disease day and NF1/NF2/Schwannomatosis dedicated days), socials and a dedicated telephone number ("Pronto Linfa" Eng. Transl. "Linfa answering") allow a bilateral confrontation between patient and expert. Furthermore, Linfa contributes, in a network with other associations (Uniamo, Anf OdV and Ananas APS) to support concrete actions at the regulatory and awareness level, in particular with the Department of Health of the Italian regions that are poorly organized for rare diseases. Recently, the Association became part of the Eurordis net. The association has an administrative office, two part-time administrative employees and a Board of Directors made by seven volunteers members. All the functions of the association are regulated by a statute. The president is the legal representative of the Association and decisions are taken by majority vote by a board of seven people including the president himself. The supreme executive organ that approves the final balance sheet and budget estimate and makes decisions on the strategies of the association activities is the Assembly of the members, which is held once a year. I have been part of the Linfa association since 2010 when we adopted our daughter affected by Neurofibromatosis type 1. In 2018, I was elected president of the association ad interim; the preliminary tasks in the Linfa Association were related to scientific research activities since I'm an assistant professor at the University of Padova. I have made my scientific knowledge available to people with rare diseases and their families, by translating scientific and clinical information in an understandable language. I'm writing articles published on our socials, explaining to patients their disease, making them understand the language of scientists and physicians, and provide instruments to improve their knowledge by them self. More importantly, I established a two-way communication channel with people and their families through

socials and a telephone service to answer questions and take demands, thus, potentiating patient empowerment and involvement. In parallel, I encouraged clinical and basic research projects by establishing research networks with excellences of the Italian (Besta Institute of Milan, Umberto I and Bambin Gesù' Hospitals of Rome, Gaslini Hospital of Genova, Burlo Garofolo Hospital of Trieste, University of Padova) and foreign NFs (Paris) centers. Currently, Linfa is financing 2 projects fully dedicated to Neurofibromatosis type 1 disease. We also set up awareness initiatives in the Veneto Region first, then in Italy, and began to collaborate with other associations. I increased the social projects, and strengthened the national collaborations by either enrolling Linfa in the Uniamo alliance or organizing projects with other Italian Associations. I increased my knowledge to be up to the task of representing patients in Eurordis, attending the Eurordis Summer School and the Eupati Italia Patient Academy, where I was subsequently elected as a member of the technical committee. My interaction with people affected by rare diseases has raised my awareness of their condition and the problems they face daily. Thus, I am highly motivated to bring their concerns to both Italian and European regulatory committees, especially in the EMA Committee for Advanced Therapies.

#### Memberships

BOOK CHAPTER 2020 Gianluca Tadini, Eric Legius, Hilde brems, Federica Chiara (2020). Multidisciplinary approach to Neurofibromatosis Type 1. Springer book 86905578. In: Gianluca Tadini Eric Legius Hilde Brems. (a cura di): Gianluca Tadini, Multidisciplinary approach to Neurofibromatosis Type 1. Chapter 10 Mechanotransduction and NF1 Loss\_Partner in crime: new hints for Neurofibroma Genesis. vol. Unico, p. 149\_159, Switzerland:Springer book 86905578, ISBN: 3319924494 2 2006 CHIARA, FEDERICA (2006). Apoptosis and Disease: Unbalancing the Survival Equilibrium. In: ALAN J. CORVIN. New Developments in Cell Apoptosis Research. p. 1\_52, NEW YORK:NOVA Science Publishers, Inc. Maya Columbus, ISBN: 9781600214530 3 2006 CHIARA, FEDERICA, RASOLA, ANDREA (2006). Apoptosis and Disease: Unbalancing the Survival Equilibrium. In: A.J. CORVIN. New Developments in Cell Apoptosis Research. p. 1\_52, Nova Publishers Conferences: 2010 L. RONCONI, C. MARZANO, F. CHIARA, A. TREVISAN, D. FREGONA (2010). Latest insights into the anticancer activity of gold(III)\_dithiocarbamate complexes. In: 10th Workshop on Pharmaco\_Bio\_Metallics. Pozzuoli (NA) (Italy), 29\_30 Ottobre 2010, p. 43 Children's tumor foundation Conferences 2016\_2021

#### Other Relevant Information