

Spotlight on....

CONTICANET

Harmonising connective tissue cancer research and treatment development

The CONNective TIssue Cancers NETwork to integrate European Experience (CONTICANET) is dedicated to promoting research into the connective tissue cancers in adults, adolescents and children. Funded by the European Commission's Sixth Framework Program (LSH-2004-2.2.0-1), this Network of Excellence kicked off in February 2006, funded for a five-year period. Connective tissue cancers include more than 50 different rare tumours. Within the European Union, incidence is not well known, but considered to be between 2-6 per 100,000 persons per year. Connective tissue cancers, including sarcomas, GIST, aggressive fibromatosis and hamartomas affect children, adolescents and adults, constituting 2% of adult cancers and 15% of paediatric cancers. As with many rare diseases, the low number of cases per country per year hinders efforts to further the understanding of these cancers, as well as the development of treatments. CONTICANET is thus generating a critical mass of key stakeholders in order to rectify the obstacles caused by data fragmentation, researcher mobility, and the heterogeneity of both methodologies and legislation. The CONTICANET network includes some 250 researchers and physicians, making it one of the largest concentrations of "molecular research and clinical pharmacological transfer" in the world focusing on connective tissue cancers. The network seeks to harmonise efforts by promoting joint research activities, establishing standard operating procedures, and making available common databases and tissue banks.



A [consortium](#) of 20 different organisations – major cancer centres, academic institutions, and private enterprises – hailing from nine different European countries (Belgium, France, Germany, Ireland, Italy, the Netherlands, Spain, Slovenia and the UK) is creating the environment necessary to facilitate collaborative research efforts by developing standardised procedures that will help propagate excellence in the field. The consortium members contribute 70% of all European and 30% of all worldwide peer-reviewed relevant publications. Various members bring to the table a portfolio of more than 30 innovative agents at various stages of development and screening technologies unavailable outside the consortium. Each of the network's partners is contributing its own particular expertise to the project:

Two years into the project, the network of excellence can already tick off several goals as "completed" or "in progress": A database of scientific projects, resources, technology platforms, and a manual of data quality have all been established and placed on websites. These will be updated regularly. More than 30 novel multidisciplinary research projects have been launched, investigating original topics in the areas of molecular characterisation, epidemiology, biochemical characterisation and preclinical pharmacology, clinical and translational research and loco-regional, none of which have previously been addressed by the

partners prior to the establishment of CONTICANET. Several barriers to innovative treatment development and diagnostic approaches have been identified by the Network members, relating to the rarity of these tumours and the need for better communication. A specific task has been identified to work with patient advocacy groups to help dismantle these obstacles. Contact with the EMEA has also been forged and is expected to facilitate treatment and diagnostic developments. Through funding exchanges, meetings, and workshops, CONTICANET has become a fruitful platform, generating innovative projects. This has already resulted in some collaborative publications, despite the short life of the Network. It is expected that additional research projects and innovative clinical trials building on the synergies between partners from CONTICANET will continue in the years to come.

An exchange between students and researchers started in the first years, and is now expanding rapidly. The integration of novel partners in order to help the network to reach its goals is also underway. One academic partner (Warsaw), one academic organisation (EORTC), and four patient advocacy groups were identified at the end of 2007 as future novel partners for the Network.

Indeed, involving patient organisations in the network is an important feature of CONTICANET. With rare diseases, such as the connective tissue cancers, the “expert patient” can be an important resource. In collaboration with 17 European Patient Advocacy Groups, CONTICANET is studying what role informed and competent patients can play within the network. This task force also wants to see how involving patient enrolment in clinical trials could be enhanced with the help of patient organisations. Patients serve a vital role in furthering the research, whether as tissue donors, participants in clinical studies, or supporters of fund-raising events.

With the status of associated partners, all these new partners will have full access to the information on the network to which they contribute. The Network partners have also selected special topics which need specific attention: paediatric sarcomas, sarcomas in adolescents, innovative approaches in local treatments - including radiotherapy, hadrontherapy, isolated limb and organ perfusion, and loco-regional treatments using nano designed particles.

CONTICANET has supported the creation of a compliance handbook for GIST patients taking imatinib in order to help both patients and oncologists monitor the patient’s management of their medication (compliance). The handbook contains a non-compliance log that the patient can fill out and show to their treating physician in order to better monitor and manage compliance with treatment.

CONTICANET has promoted pocket-sized identity cards (currently available in French and English languages) for GIST patients to carry, containing vital information particular to their disease and the treatment they are undergoing. These identity cards, developed by patient advocacy groups, provide contact information for the patient’s treating oncologist, as well as the specific diagnosis the patient has received, the dosage of medication the patient is taking, a list of substances that can interfere with treatment efficacy, and monitoring recommendations. Other projects in the works include developing criteria for rare disease centres of expertise in the field. This development will enhance harmonisation between centres across Europe.

CONTICANET is also producing handbooks for GIST and sarcomas destined for professionals. An information source, to be called “Sarcomedia” is being developed by and

for patients and the public. Finally, the first CONTICANET newsletter is expected to be released in the next two months at the ASCO 2008 annual meeting.

In coming years, the network will work hard to improve the management of patients with connective tissue tumours by increasing the knowledge on nosological classification of these tumours, improving management in the clinical setting, as well as in the laboratory, and in the late post treatment phase, for both, in localized and advanced phases, facilitating the development of novel agents, and limiting the long term side effects in particular in paediatric and adolescent patient populations.

As the network plans to continue autonomously after the five-year funding period - strategies to enable sustainability have been agreed upon with the creation of a non-profit- status association as the first step to creating a legal entity to host the activities of the network in the future - it is expected that CONTICANET will continue to spread excellence in several directions: enlarging the network with other academic and private organisations; continuing to enhance relations with the EMEA, health authorities and insurance bodies; and supporting and collaborating with patients through advocacy groups or cancer leagues, all these actions leading to an integrated sustainable structure - a European research foundation able to support integrated research actions and make available new treatments for connective tissue cancers.

[Visit the CONTICANET website:](http://www.conticanet.eu/html/) <http://www.conticanet.eu/html/>

Contact CONTICANET: simon.bacconnier@conticanet.eu