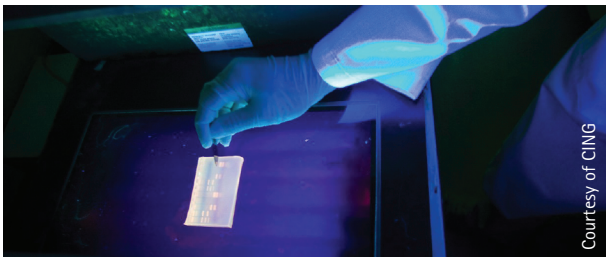




## EUMEDCONNECT2 Case Study ITHANET: e-Infrastructures revolutionising thalassaemia treatment



Thalassaemia and its related conditions – inherited blood disorders – affect some 300,000 newborn infants worldwide every year. Funded by the EU, the ITHANET project is facilitating and strengthening research into thalassaemia by helping scientists across Europe and the Mediterranean share medical expertise – bringing about a clear improvement in treatment for the large group of sufferers in the Mediterranean region, especially vulnerable children. The project relies on the power of two high capacity state-of-the-art data communications networks designed, built and operated by DANTE: EUMEDCONNECT2, bringing together researchers in the Mediterranean countries, and GÉANT2, serving the European research and education community.



Courtesy of CING

### The ITHANET project

ITHANET – the Electronic Infrastructure for Thalassaemia Research Network – is transforming the outlook for children affected by the disease. Without effective treatment, thalassaemia is usually fatal within the first decade of life. Prevention of the disease is of primary importance both in saving lives and in reducing the burden on health services around the world. There has been considerable success implementing preventative programmes in European countries such as Cyprus, Greece and Italy, but countries with poorer economic resources face considerable obstacles to effective treatment.

Supported by the European Commission through its 6th Framework Programme for Research and Technology Development (FP6), ITHANET aims to link Mediterranean research centres working on thalassaemia and its related conditions with those in the wider European research community. Using the power of the high-speed EUMEDCONNECT2 and GÉANT2 networks, ITHANET enables researchers in this field to exploit the power of e-Infrastructures. It allows them to co-operate in multi-centre studies, to exchange information, to provide second opinions using video conferencing and to develop effective treatments and innovative drug therapies.

Until the launch of ITHANET, the existing understanding and experience of treatment was spread unevenly amongst a variety of research centres, limited in their ability to co-operate by the very basic e-Infrastructure tools available. ITHANET has introduced a range of advanced tools, including videoconferencing, grid computing and e-learning, that together are strengthening research throughout the Mediterranean region and bringing benefits to people to whom sophisticated diagnostic and treatment programmes were inaccessible.

### ITHANET – using the power of e-Infrastructures to save lives

ITHANET is an information and communications environment. It focuses a set of powerful e-Infrastructure tools on the needs of researchers, clinicians, patients and the public, giving them the ability to carry out collaborative research, to pool resources, to exchange data and to disseminate research results efficiently and cost-effectively. Using the powerful EUMEDCONNECT2 and GÉANT2 network infrastructure, it aims to set up a global network for health professionals working in the field of haemoglobinopathies. As at September 2008, ITHANET brings together 26 research establishments in Cyprus, the Czech Republic, Egypt, France, Greece, Israel, Italy, Lebanon, Malta, Netherlands, Rumania, Spain, Switzerland, Tunisia, Turkey and the UK.

### Thalassaemia – Mediterranean anaemia

So named for the fact that its sufferers tend to live near the sea ('thalassa' and 'haemia' are the Greek words for 'sea' and 'blood'), thalassaemia is the most prevalent of a group of blood diseases called haemoglobinopathies – all inherited genetic disorders of haemoglobin, the red blood cell molecule that carries oxygen. Haemoglobinopathies compromise the ability of blood to carry oxygen to where it is needed.

Without adequate treatment, the disease can be fatal and can give rise to a range of painful and debilitating conditions – enlarged liver and spleen, heart failure, retarded growth and endocrine disorders. The disease is particularly common amongst populations originating from both the European and the North African margins of the Mediterranean basin. EUMEDCONNECT2 brings together scientists in the major centres in this region and so is particularly well suited to supporting research into the disease.

### EUMEDCONNECT2 – the research and education network for the Mediterranean

- Directly connecting southern and eastern Mediterranean partner countries: Algeria, Egypt, Jordan, Morocco, Palestine, Syria and Tunisia.
- Connecting other Mediterranean and European partners via GÉANT2
- High capacity Internet connectivity for academic and scientific collaborations
- Takes forward Mediterranean region e-Infrastructures pioneered by EUMEDCONNECT since 2004
- Jointly funded by the European Commission and the Mediterranean partners to reducing the digital disparity between the Mediterranean and European regions





## EUMEDCONNECT2 Case Study

### ITHANET: e-Infrastructures revolutionising thalassaemia treatment

#### Supporting the ITHANET community

The rich variety of e-Infrastructure tools used by ITHANET supports the fast-moving field of haemoglobinopathy research and offers speedy access to news, communications systems, streamed online training courses and grid computing facilities.

##### ITHANET

- improves communication between partners
- gives direct universal access to databases and libraries
- enhances multi-party dialogue, supporting scientific work-group meetings with videoconferencing
- encourages the sharing of best practice, particularly with regard to clinical protocols
- enables practical telemedicine such as remote consulting
- provides widespread easy access for viewing meetings and conferences
- enables time-saving, cost-effective remote training



Over the years thalassaemia researchers in Mediterranean countries have developed considerable expertise in diagnosis and effective treatment, but these centres of excellence remained isolated, unable to undertake any really effective co-operation. ITHANET has transformed this picture, and promises great strides for the future in our ability to understand, treat and prevent this disease. EUMEDCONNECT2 gives us this opportunity to share local insights and experience and to work together for common solutions.



**Dr Marina Kleanthous, Head of Molecular Genetics Thalassaemia Department at the Cyprus Institute of Neurology and Genetics (CING) and Project Co-ordinator of ITHANET**



#### Innovative drug design

Work is underway in the ITHANET community to use the power of EUMEDCONNECT2 to leverage the technical work of research institutes across the European mainland and the Mediterranean fringe. Dr Marina Kleanthous and Dr Christos Shammas, of the Cyprus Institute of Neurology and Genetics (CING), are involved in one initiative to develop a grid-enabled application to model the detailed molecular behaviour of a wide variety of drugs in order to assess their suitability as therapies for the treatment of thalassaemia. This activity will draw together the efforts of researchers at CING, the Makarios Hospital in Cyprus, the Erasmus Medical Centre in the Netherlands and ThalLab at Ferrara University in Italy.

The ITHANET community is also investigating the possibility of using grids and their underlying network infrastructure for other applications that require the rapid and secure transfer of large volumes of data, including management of patient records, comparison and evaluation of MRI techniques and the diagnosis of thalassaemia-related osteoporosis.

#### Finding a safer alternative to blood transfusion

E-Infrastructures are powering collaborative research between ThalLab in Ferrara, Italy and the University of Cairo, Egypt. The project – led by Professors Roberto Gambari and Amal El-Beshlawy and building on research by Professor Eitan Fibach at another ITHANET partner, the Hadassah University Hospital in Jerusalem – is looking for drug-based alternatives to blood transfusion, currently the principal treatment for thalassaemia.

Although transfusion is a life-saving therapy, there is a risk to patients of transmitted infections and viruses, like hepatitis – a substantial risk in less developed countries where blood reserves are scarce and screening is less advanced. This project is using the flexibility and power of grid computing to seek and develop chemical compounds that can induce the production of haemoglobin as an alternative therapy to transfusion.



The Egyptian Thalassaemia Association is working hard to reduce dependency on expensive and frequently unsafe transfusion therapy. E-Infrastructures are enabling us to study and experiment with drug-based alternatives, to conduct clinical trials across several research sites and to draw on the expertise and insight of scientists across Europe. It is therefore difficult to overstate the importance to thalassaemia sufferers of the existence of reliable data networks like EUMEDCONNECT2 and GÉANT2.



**Professor Amal El-Beshlawy, Pediatric Haematology Department El Monira University Hospital, University of Cairo and President of the Egyptian Thalassaemia Association.**



*This document has been produced with the financial assistance of the European Union. The contents of this document are the sole responsibility of DANTE and can under no circumstances be regarded as reflecting the position and opinions of the European Union.*

#### Find out more

To learn more about ITHANET and its work, visit: [www.ithanet.eu](http://www.ithanet.eu)

Find out more about EUMEDCONNECT2 from: [www.eumedconnect2.net](http://www.eumedconnect2.net)

Find out more about GÉANT2 from: [www.geant2.net](http://www.geant2.net)

DANTE is a non-profit organisation that operates the GÉANT2 and EUMEDCONNECT2 networks. Further information about DANTE and its activities can be found at: [www.dante.net](http://www.dante.net)