

Developing a Thalassaemia Web Portal

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Abstract The frequency of haemoglobinopathies, such as sickle cell anaemia and the thalassaemias, and their potential severity make disease prevention an absolute requirement for affected countries. The global movement of disease carriers has extended this task, and has expanded the medical and research community drawing on existing information and endeavouring to develop advanced diagnostic tests and therapies. These developments call for a coordination of international databases, research efforts and medical support, and has led the *Ithamet* consortium, dedicated to improving the electronic infrastructure of thalassaemia research, to conceive a thalassaemia web portal as an essential tool to meet this challenge. The proposed content and functionality of the web portal are presented in this poster.

Introduction International patient organisations and Euromediterranean research centres conducting molecular and clinical research of thalassaemia and related haemoglobinopathies united in April 2006 for a time frame of two years to form the *Ithamet* project (www.ithamet.eu). The 25 participants from 16 countries aim to harmonise and develop existing resources, such as comprehensive databases, research experience and clinical expertise, and make them accessible for the coordination of existing activities and as a basis for collaborative projects. As a key tool to achieve this goal, *Ithamet* envisages a thalassaemia web portal as a repository for shared methods and data, and as a means to interface in search for information, materials, and collaborators. The portal will draw on incorporated databases and the expertise of its users to become a primary port of call also for interested members of the public and thalassaemia patients in search of information and support. The portal is currently in development, and its facility as a daily tool will benefit from the input of everybody involved in thalassaemia research and patient care.

The Portal The portal has two separate main menus, one for the lay public and one for expert users, to integrate the disparate demands of both user groups. Menu items marked with an asterisk (*) indicate features that allow registered users the submission of data by choosing a dedicated on-line submission form in the sub-page. Where appropriate, contributions can be targeted to the *General Menu* and/or the *Specialist Menu*. The *General Menu* will include

General Menu

- General Resources
- Introduction to Thalassaemias
- News and Events *
- General Exchange *
- Thalassaemia Organisations *
- Medical Support Abroad *
- Ask An Expert *
- External Links *

- a brief introduction to the thalassaemias, with annotated external links for more in-depth reading
- news and events (new submissions to the portal, drug development, books, presentations, and broadcasts)
- an exchange (a thread-based discussion interface for the exchange of experiences)
- a list of thalassaemia organisations
- a list of national support centres for patients on the move
- an interface to ask thalassaemia experts by starting a highlighted thread in the *Specialist Exchange* below
- external links of relevance to thalassaemia patients and the interested public.

Specialist Menu

- Specialist Resources
- News *
- Meetings and Conferences *
- Research & Diagnostic Groups *
- Thalassaemia Collaborations *
- Specialist Exchange *
- Internal Resources
- External Resources *

- *Ask An Expert* questions and responses will be stored in searchable databases, as will be threads of the *General Exchange* after a time of inactivity. Providing partially overlapping functionality, the *Specialist Menu*, targeted at clinicians and researchers, will include
- news (new submissions to the portal, drug development, books, presentations, and broadcasts)
- meetings and conferences (including contact details and URL)
- a collection of research and diagnostic laboratories (including contact details, interests, and URL)
- a collection of multi-centre collaborations (including contact details of the coordinator, aims, time frame, and URL)
- an exchange (a thread-based discussion interface for the exchange of experiences and expertise)
- a collection of databases maintained on or interfaced by the web portal for data mining and display on-site
- a collection of external databases as external links or with only basic integration for data mining.

The *Specialist Exchange* will contain a dedicated form to submit requests for short- and long-term collaboration, and to seek or offer employment. *Internal Resources* will hold databases of clinical guidelines, protocols, application and trouble-shooting notes, preliminary results, and relevant documents by public funding bodies. *External Resources* will interface with HbVar and other databases, including HGMD, and specific NCBI and ENSEMBL resources. The portal will have a flat menu structure, will be maintained indefinitely, and all submissions will be reviewed and edited before they go on-line.

Other Features

- Register/Log In
- Feedback/Suggestions *
- Search This Site
- ?

Maintenance and growth of the portal will be facilitated by

- registration of contributors, to reduce abuse of submission and exchange functionality
- a dedicated submission form for feedback on content, interfaces, dead links, and to suggest new functionality.

The portal will also be fully searchable by keyword, to reduce the learning curve in making it a useful tool and to avoid frustration with the retrieval of related information stored in separate databases. Critically, the portal is intended to grow and change in order to meet the needs of its users and will rely on their steady feedback to turn into a daily web site of choice.

Conclusions The *Ithamet*-initiated web portal for the thalassaemias and related haemoglobinopathies is still in its conception. It will be designed to facilitate disease prevention on an international level, and to promote the development of new diagnostic tests, of symptomatic therapy and of a cure for the thalassaemias, in collaboration or by exploiting the portal as a knowledge base. Your ideas are already welcome (lederer@cing.ac.cy).