

# Health-e-Child Newsletter



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## A Health-e-Child Clinical Application

### *What impact will Health-e-Child have on the daily clinical practice and biomedical research in JIA?*

Juvenile idiopathic arthritis (JIA) is the most frequent rheumatologic disease in paediatric age and represents a very heterogeneous condition that lumps together all forms of chronic arthritis of unknown origin, with onset before 16 years of age. It is characterized by chronic inflammatory process involving synovial membrane, with potential risk of developing progressive eroding process of the cartilage and the bone proximal to the inflamed joint with serious functional disability.



*Fig. 1 A conventional radiographic image showing bone erosions of the left femoral head*

The clinical objective of Health-e-Child (HeC) is to increase the practicing physician's knowledge of disease features and of predictors of outcome, by integrating information from all available sources - clinical, imaging, and biologic data - collected during routine care. The final aims of the project are:

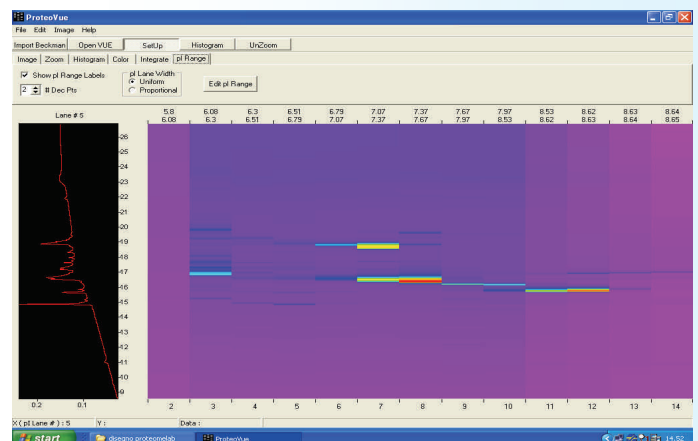
- to improve JIA classification with the identification of more homogeneous groups suitable for etiopathogenic studies;
- to find early predictors of poor outcome that allow the early identification of patients who require a more aggressive treatment;
- to identify sensitive signs of joint damage progression to be used in clinical trials to assess the disease-modifying effect of the tested drugs.

Analyzing through vertical integration the information from all of these sources that the HeC database will host will afford the clinician the opportunity to identify more homogeneous subgroups of patients, classified not only on

clinical grounds, but integrating radiological, immunological and molecular findings. A better classification of JIA, with the identification of disease subgroups homogeneous in terms of clinical and biologic features, evolution and sensitivity to treatment will be germane to efforts aimed at tailoring therapy according to the specific needs of each subgroup. Moreover, studies aimed at understanding the causes and mechanisms of the various diseases have little chance of generating any impact if performed on groups that are not homogeneous. From this standpoint, HeC represents a concrete step towards bridging clinical and basic investigations on the etiological aspects of JIA.

The availability of new potent therapeutic agents for children with JIA requires, on the one hand, the early identification of the patients who are most likely to develop joint damage, while on the other, the use of more sensitive imaging modalities to assess joint damage in order to evaluate drug efficacy. During the data integration process, the HeC system merges information to construct models of JIA courses, building on a collection of known cases, each annotated with biomedical data and expert diagnosis or known outcome. Through a sophisticated multi-disciplinary analysis of all data it will be possible:

- to discover baseline magnetic resonance imaging (MRI) measures (i.e., degree of synovitis, bone marrow oedema, etc) that are more predictive of future severe radiological damage;
- identify a panel of candidate gene in JIA that can predict erosive disease;
- determine whether there are serum and synovial protein profiles predictive of disease course.



*Fig. 2. The HeC proteomic approach: bi-dimensional liquid-liquid chromatography of a JIA patient's serum*

By means of the vertical integration of all of the information and data coming from these heterogeneous sources and through the comparison of similar cases it will be possible in the very near future:

- ❑ to predict the long term outcome at an early stage of disease course;
- ❑ to identify the patients who require a more aggressive treatment at an early stage;
- ❑ to predict the pharmacological response to treatment.

The ability to quantify synovitis and damage in JIA and to measure the changes in these aspects of the disease is crucial to efficient evaluation of the therapy efficacy. To date, in clinical trials, drug efficacy is judged only on clinical parameters (e.g., swollen and tender joint counts), since measures that can allow the early identification of the progression of joint damage, and therefore of drug efficacy on disease progression, are not available.

The strict collaboration with experts in information technology in the HeC project will make it possible to generate the most sophisticated techniques to judge drug efficacy in the short term (i.e., MRI synovial volume membrane changes, MRI erosion volume changes, etc).

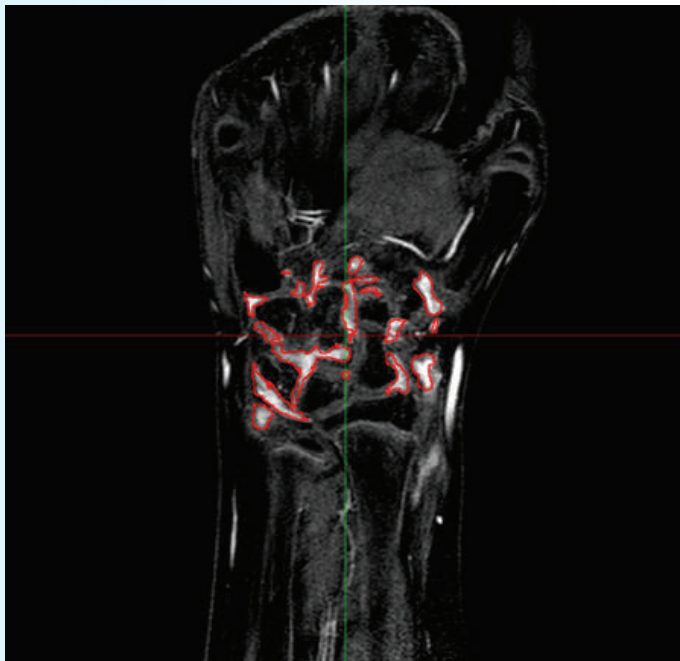


Fig. 3. JIA wrist MRI: the synovial membrane is outlined in order to evacuate total synovial membrane volume.

Furthermore, the creation of an MRI and ultrasound (US) scoring system to quantify JIA pathology represent a first step towards developing among the three centres participating in the study - the Istituto Giannina Gaslini of Genova (IT), the Hôpital Necker-Enfants Malades of Paris (F) and the Great Ormond Street Hospital of London (UK) - a common agreement on US and MRI detected JIA pathology, to provide a common reference point of communication, a shared language from which ongoing studies can build optimal system for measuring the JIA lesions of interest.

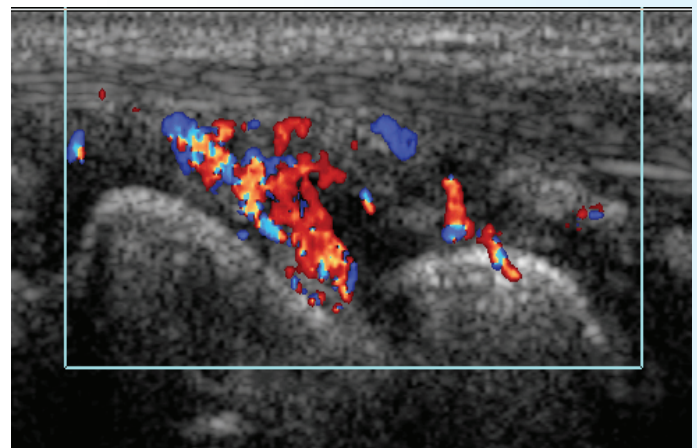
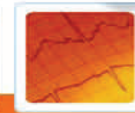


Fig. 4. JIA wrist US: a colour Doppler US image showing synovial hyperemia in the mid-carpal joint

In conclusion, the HeC system will invariably evolve into a valuable tool that will enable the physician to appropriately plan the most suitable treatment strategy, one that is specifically tailored for the child's radiological picture, gene and proteomic expression profile. Moreover, the integration of data emerging from these different sources will in all likelihood provide important insights for further research on the diagnosis, damage prevention and treatment of these diseases.

For information on HeC clinical activities in the area of paediatric rheumatological disorders, contact [Prof. Alberto Martini](#) or [Dr. Clara Malattia](#) c/o the Istituto Giannina Gaslini.



## Health-e-Child launches its dedicated training activities

As the clinical applications and tools that Health-e-Child (HeC) endeavours to develop become available, medical professionals must be put in a position to take advantage of them. This is the premise that drives the project's Workpackage 15 on Training, whose central objective is to design and deliver state-of-the-art training actions, to both the Consortium and the larger biomedical community.

Bringing its 20 plus years of experience in the training and continuing medical education of health care professionals to the project is the [European Genetics Foundation](#) (EGF). Key to the successful achievement of EGF's tasks will be their adherence to a tested methodology, whereby



- ❑ specific stakeholders' training requirements will be analysed and created;
- ❑ a methodology to be followed in order to satisfy the expressed requirements will be detailed;
- ❑ training packages for each of the target communities will be designed.

At a secondary - but no less important - level, project-endorsed training activities will surely prove to be an important means of dissemination, attracting the attention of industrial clusters and ideally leading to the involvement of other researchers and research themes that were not envisaged at the outset of the project.

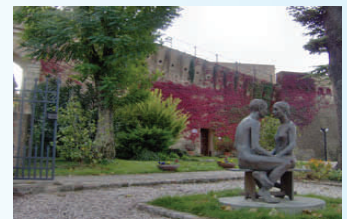
The first of three foreseen courses - designed to specifically address the medical domains tackled by the project - "Genetics of Rheumatic and Auto-inflammatory Diseases" took place this past April 1 - 4 2007. (A lengthier account of the event follows below.)

Two more courses to be held over the next 2 years are currently in the planning stages: "Cardiogenesis and Congenital Cardiopathies: from Developmental models to Clinical Applications" and "Infantile Brain Tumours and the Use of Integrated Databases". Indeed, this latter event will likely provide the first occasion to demonstrate the Health-e-Child system using the field of infantile brain tumours (gliomas in particular) as a paradigm.

## The First Health-e-Child Training Event

Health-e-Child kicked off its training activities this past April 1-4, 2007 in the magnificent surroundings of the EGF's main training venue of Bertinoro (Bologna, Italy) with the training course "Genetics of Paediatric Inflammatory Diseases".

Jointly organized by HeC partners EGF and Istituto Giannina Gaslini (IGG) under the Direction of IGG Professor Alberto Martini, this hybrid, interactive web-cast event featured a roster of internationally acclaimed faculty to examine the multifactorial aspects of paediatric rheumatic diseases and the increasingly evident genetic component that affect both disease susceptibility and disease outcome.



*The EGF's Bertinoro venue*

This intensive four-day course welcomed 17 faculty members and 24 participants from over 13 countries (including, the U.S. and Brazil).



*Attendees and faculty at Bertinoro* (see photo below) - joined in to "attend" the event in streaming.

Moreover, no fewer than 30 participants from 6 remote locations from throughout the world - Germany, Greece, Italy, the U.S. and Tunisia

Participants were treated to a special session devoted to HeC's groundbreaking research objectives to vertically integrate biomedical information - including genetic data - into the diagnosis, prognosis and therapy of paediatric rheumatic diseases.



*Tunisian participants attending in streaming*

For further details on the course proceedings - including on-demand video of the lectures delivered in streaming - visit the [EGF website](#).

## Health-e-Child at OGF-20/2nd EGEE User Forum

From the 7<sup>th</sup> to the 11<sup>th</sup> of May 2007 the [20<sup>th</sup> Open Grid Forum](#) (OGF) was held in Manchester, UK, collocated with the [2nd Enabling Grids for E-Science \(EGEE\) User Forum](#).



The Health-e-Child (HeC) consortium was one of 23 sponsors present at the Forum with an exhibition booth throughout the week. With

an attendance exceeding 900 members of the grid community from around the world, the Forum was designed to "develop Grid standards, showcase real-world applications, discuss large-scale grid infrastructure techniques and applications, workshop Enterprise and eScience's best practices and present business case studies and solutions".



The HeC booth was permanently staffed by William McFadden from HeC Partner [Lynkeus](#), S.r.l. in Rome, who was able to count on the intermittent technical support of HeC Partner Representatives Jörg Freund from [Siemens Medical Solutions](#) and David Manset from [Maat GKnowledge](#).

As an introduction to the project, the HeC booth used a self-standing slide show that was both accessible to passers-by and detailed enough for attendees to understand the interesting space that the project occupies within the grid community.

More specifically, the HeC booth put on display two posters produced by members of the consortium. The first was designed by HeC Partner [University of the West of England](#) (UWE Bristol, UK), and was focused on how HeC is developing an integrated biomedical information model, supported by sophisticated and robust search optimisation and matching techniques for sorting out and deciphering heterogeneous and multicentric data.



HeC Coordinator Jörg Freund and Lynkeus' William McFadden

The second poster

was produced by Maat Gknowledge, this poster was about the horizontal and vertical data integration approach that is being implemented as part of the HeC platform.



HeC Coordinator Jörg Freund with a Forum participant

There was also a video demonstration of the state-of-the-art healthgrid platform that is unique to HeC, highlighting key aspects of the system such as security, patient data privacy and how the project optimizes the use of its grid infrastructure for addressing key clinical challenges. The work that Maat Gknowledge has done in this field attracted a lot of interest from many attendees at the forum, which at the same time revealed itself useful for comparing technical progresses with other projects/initiatives. These technical aspects were also presented at the Life Sciences Group workshop, which allowed for further exchanges within the community.

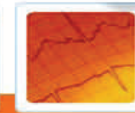
The forum was considered to have been a great success as Steve Crumb, OGF VP of Operations, remarked, "Honestly, I was blown away by the great attendance and by the synergies resulting from bringing the EGEE and OGF communities together. This event clearly provided the content desired and the open forum where connections could be made."



David Manset (left) explaining the fundamental premises of the HeC platform to interested attendees.

All the handouts, posters, and presentations that were made available at the booth are now available on the [HeC web portal](#), which also contains all information pertaining to the consortium's presence at upcoming events.

Indeed, a follow-up appearance of HeC will no doubt come about at [EGEE'07](#) (Budapest, 1-5/10/2007), the key European event dedicated to grid technologies.



## Events & Announcements

### Health-e-Child at the BELIEF-EELA Conference on e-infrastructures

BELIEF (Bringing Europe's eElectronic Infrastructures to Expanding Frontiers) is an EU 6th Framework Programme funded



project whose aim is to promote European e-infrastructures to other parts of the world as well as to diverse communities. In taking this message to the Southern hemisphere, BELIEF recently teamed up with EELA (E-infrastructure shared between Europe and Latin America), another EU funded initiative, to stage a major conference in Rio de Janeiro from June 25 to 28. Invited to present Health-e-Child (HeC)

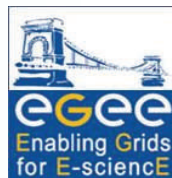


was Yannis Ioannidis of the University of Athens (also a partner in BELIEF). Indeed, the venue offered an ideal setting to deliver the shared message and vision that e-infrastructures constitute an answer to several of the most complex challenges presented by the worlds of biology and medicine, (the processing of huge numbers of cases, experimental results, the integration of data), as well as to create an exchange for ways to chart the incorporation of e-infrastructures and grid technologies in the mainstream of biomedical research.

### Future Venues for Health-e-Child

A brief reminder of where HeC will be in the coming months:

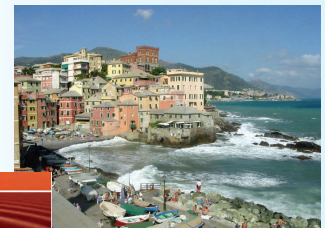
- ❑ The Consortium will continue to be a "presence" at EGEE gatherings with a concerted appearance at EGEE'07 (Budapest, October 1-5, 2007), the key European event dedicated to Grid technology.
- ❑ "eHealth: Combining Health Telematics, Telemedicine, Biomedical Engineering and Bioinformatics to the Edge" organised by the eHealth Competence Center Regensburg (CeHR) (Regensburg, Germany, December 2-5, 2007), an international event bringing together leading experts representing all domains involved in eHealth.



### The Genoa Festival of Science

A special occasion for achieving a broader general public dissemination of HeC will be offered by the Genoa "Festival of Science" (October 26 to November 6, 2007). Organised for the past four years and arguably one of the most popular and well-attended "science communication events" in Europe, with over 250,000 visits at 90 venues throughout the city, the 13-day Genoa festival brings together world renown experts (including Nobel laureates) in fields ranging from astrophysics to biological/medical sciences, from mathematics to nanotechnologies, in a multifaceted programme of exhibits, conferences and laboratories aimed at promoting greater public awareness and understanding of science & technology.

To showcase its overriding vision of personalised medicine afforded by scientific and technological breakthroughs, such as those being explored in the areas of vertical data integration, knowledge discovery and decision support systems, HeC Representatives will



preside over a 1/2-day forum to

illustrate the project as an anticipation of the structural problems that all healthcare systems will face in trying to adjust to future demographic changes, explaining the rationale of its ambition for becoming the universal paediatric knowledge repository and communication conduit for future policy makers. Indeed, pains will be taken to involve leading international, national and local authorities and stakeholders.

The session, tentatively scheduled for the morning of October 27th, will focus particularly on the assumption that existing healthcare processes and models will likely be unable - over the next decade - to cope with increasing demographic change, increasing demand and growth in expectations, unless coordinated European public policies begin to more effectively implement innovative e-Health solutions, such as that pursued by HeC.

Further details on the session will be published on both the HeC and Genoa Science Festival web sites as they become available.



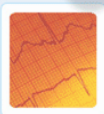


## Health-e-Child FactSheet

### Health-e-Child in figures

|   |                                      |
|---|--------------------------------------|
| Project Identifier                      | IST-2004-027749                      |
| Timeframe                               | January 1, 2006 to December 31, 2009 |
| Total cost                              | 16.7 million €                       |
| European Union funding                  | 12.2 million €                       |
| Number of partners                      | 14                                   |
| Number of Workpackages                  | 16                                   |
| Number of Deliverables (at 18 months)   | 38                                   |
| Total estimated efforts (in man/months) | 2363                                 |

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### Who's Who in Health-e-Child

Coordinator and Executive Board Chairman  
 Governing Board Chairman  
 Project Management Team Leader  
 Scientific Committee Chairman  
 Technical Coordinator  
 Clinical Coordinator  
 Ethical and Legal Issues Committee Chairman  
 Intellectual Property Rights Committee Co-Chairmen

**Jörg Freund** - Siemens Medical Solutions  
**Alok Gupta** - Siemens Medical Solutions  
**Edwin Morley-Fletcher** - Lynkeus, S.r.l.  
**Dorin Comaniciu** - Siemens Corporate Research  
**Martin Huber** - Siemens Corporate Technology  
**Giacomo Pongiglione** - Istituto Giannina Gaslini  
**Alberto Martini** - Istituto Giannina Gaslini  
**Yannis Ioannidis** - University of Athens  
**Alessandro Verri** - University of Genoa

### Health-e-Child Workpackages and Workpackage Leaders

|      |   |                                   |
|------|---|-----------------------------------|
| WP1  | Project Management                                    | Siemens Medical Solutions         |
| WP2  | User requirements specifications                      | University of the West of England |
| WP3  | Legal, Ethical and regulatory issues                  | Istituto Giannina Gaslini         |
| WP4  | Privacy and security                                  | Siemens Medical Solutions         |
| WP5  | Grid platform   | Maat GKnowledge                   |
| WP6  | Medical knowledge representation—ontologies           | University of the West of England |
| WP7  | Data management layer and data integration mechanisms | Maat GKnowledge                   |
| WP8  | Medical query processing algorithms                   | University of Athens              |
| WP9  | Data collection                                       | Istituto Giannina Gaslini         |
| WP10 | Ground truth and clinical knowledge gathering         | Istituto Giannina Gaslini         |
| WP11 | Integrated disease modelling                          | INRIA, Sophie Antipolis           |
| WP12 | Decision support systems                              | Siemens Medical Solutions         |
| WP13 | Biomedical knowledge discovery                        | University of Athens              |
| WP14 | Deployment of data management system and grid gateway | Maat GKnowledge                   |
| WP15 | Training  | European Genetics Foundation      |
| WP16 | Dissemination   | Lynkeus, S.r.l.                   |

### Health-e-Child Project Support

|  |  |   |
|--|--|---|
| Health-e-Child Project Management Team | Alessandro Sattano<br>Antonella Trezzani<br>William McFadden | Lynkeus, S.r.l.<br>Lynkeus, S.r.l.<br>Lynkeus, S.r.l. |
| Health-e-Child Newsletter Editor       | Thomas Wiley   | Fondazione Gerolamo Gaslini                           |

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