



EuroGentest

[www.eurogentest.org](http://www.eurogentest.org)

# ERNDIM: did we reach our goal?

Leo Spaapen

Diepenbeek, Belgium, December 1991

## Birth of ERNDIM

*(European Research Network for evaluation and improvement of screening, Diagnosis, and treatment of Inherited disorders of Metabolism)*



GOAL of ERNDIM:

Consensus between Biochemical Genetics Centres  
on reliable standardized procedures for diagnostics,  
treatment and follow-up monitoring of  
Inherited Metabolic Diseases



## Historical milestones

January 1992: ERNDIM-I project >>BIOMED I programme

*not qualified for subsidization; too ambitious, too many topics*

February 1993: ERNDIM-II project >>BIOMED I programme

*restricted to development of quality assurance programme*



## Historical milestones

### ERNDIM-II project, goals

- analytical/methodological quality assurance program
- to achieve a high standard of quality in IDM laboratories
- alignment of reference values
- help participants to improve quality: education, feedback



## Historical milestones

May 7<sup>th</sup> 1993, first meeting of "ERNDIM expert committee"

*Topics: European Quality Assurance Programme,*

*Organization, co-ordination, supervision, finances*

*Establishment of the ERNDIM office in Diepenbeek(B)/Maastricht(NL)*

*Defining additional objectives: education, communication to participants,  
back reporting to BIOMED organization*



# Historical milestones

**ERNDIM**  
**Dr. B. Fowler**  
**Basler Kinderspital Basel**  
**Roemergasse 8**  
**CH 4005 Basel**  
**Switzerland**

**Maastricht August, 17<sup>th</sup> 1993**

Subject: 2<sup>nd</sup> meeting "expert committee".

Dear Colleague,

Firstly, it is a pleasure to inform you of the acceptance of our proposal "Development of a European quality assurance program of diagnostic analytical methods used for the neonatal and selective screening of inherited disorders of metabolism: an inter-laboratory reproducibility study (ERNDIM)" by the Commission of the European Communities.

**Secondly, we like to invite you for the 2<sup>nd</sup> meeting of the ERNDIM "expert committee" on Tuesday, September 7, 1993, at 9.30 a.m..**

Conference room 3 at the Conference Centre, Manchester has been booked for our meeting.  
For the agenda you are referred to the enclosure.

#### **Financial support for the meeting.**

Until now our efforts to raise funds for the meeting at companies for biochemical equipments were without concrete promises. Some companies will consider financial support for next year. Furthermore, we are still waiting for E.C.- support as promised by Dr.A. Dickens from the Commission of the European Communities. We ask you to keep your vouchers of travel and accommodation for possible refundment later on.  
Looking forward to meet you in Manchester,

with kind regards,  
Yours sincerely,

Baudouin François

Leo Spaapen



## Historical milestones

September 7<sup>th</sup>, 1993, second meeting of “ERNDIM expert committee”

ERNDIM-II project has been awarded by the  
Commission of the European Communities

Brian Fowler agreed to join the “ERNDIM expert committee”





## Historical milestones

January 1<sup>st</sup> 1994: Start European Quality Control Program

### *Scheme organizers*

- Amino acids: *Prof. Pierre Kamoun, Paris*
- Organic acids (quantitatively): *dr. Hans Willems, Nijmegen*
- Organic acids (qualitatively): *dr. Jim Bonham, mrs. Melanie Downing, Sheffield*
- Special Assays: *dr. Hans Willems, Nijmegen*
- Proficiency test (pilot for Benelux, Germany): *dr. Hans Willems, Nijmegen*



## Historical milestones

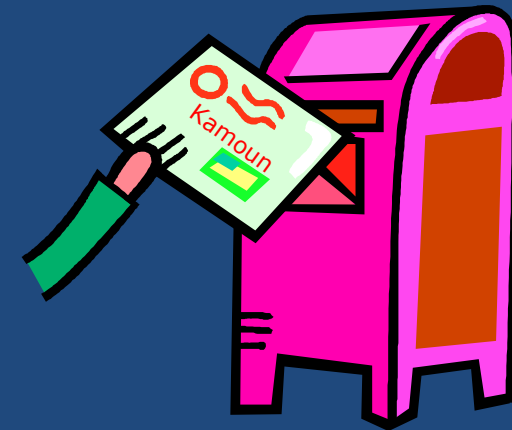
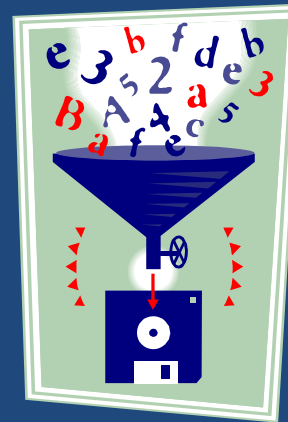
January 1<sup>st</sup> 1994: Start European Quality Control Program

Communication by:

*aa: every 3 months*

*oa (quant): every 6 months*

*oa (qual): every 3 months*



# Historical milestones

## Executive Committee:

B. François (chairman)  
J. Bonham (vice-chairman)  
J. Dhondt (treasurer)  
L. Spaapen (secretary)

## Board of Trustees:

C. Bachmann  
P. Divry  
B. Fowler  
A. Van Gennip  
P. Schadewaldt  
A. Sewell



Maastricht, September 5<sup>th</sup> 1994

Registration of Foundation ERNDIM: Public Notary &  
Chamber of Commerce



# Foundation's Memorandum and Articles of Association

OPRICHTING EN STATUTEN VAN  
STICHTING ERNDIM-QAP  
TE MAASTRICHT



— VERSTEEG & VERSTEEG NOTARISSSEN  
MAASTRICHT



SSIEM



Executive committee



Board of trustees

ERNDIM QAP



Scheme organizers

Participants in quality control schemes

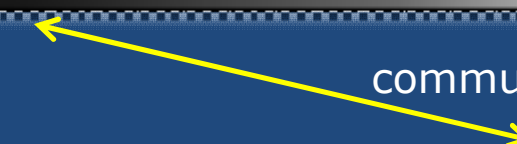


communication

communication



National expert members



# Historical milestones

## Participation in ERNDIM quality control schemes

1994 – 1996  
open for Europe



since 1996  
open for centres in  
whole world



## Historical milestones

1997 change of executive committee of the ERNDIM Foundation

Chairman: Jim Bonham

Secretary: Brian Fowler

Treasurer: Baudouin François

Scheme representative: Albert van Gennip



## Historical milestones

July 1997;

ERNDIM Quality Assurance Project Phase II accepted for subsidization by the European Commission





## Historical milestones

2001 Brian Fowler became the new Chairman of the board  
of the Foundation ERNDIM

Secretary: Ernst Christensen

Treasurer: Jim Bonham



# Historical milestones

**2005 ERNDIM partner in EuroGentest programme**  
**Network for test development, harmonization, validation and standardization of services**



BY AIRMAIL

 **newlife**  
...because some babies are very, very special!  
[www.bdnnewlife.co.uk](http://www.bdnnewlife.co.uk)



PROFESSOR B. FOWLER

ERNDIM

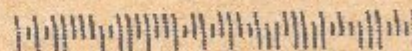
LABORATORY FOR BIOCHEMICAL GENETICS

DEPT OF CLINICAL GENETICS

MAASTRICHT HOSPITAL

PO BOX 5800

NETHERLANDS



# EuroGentest



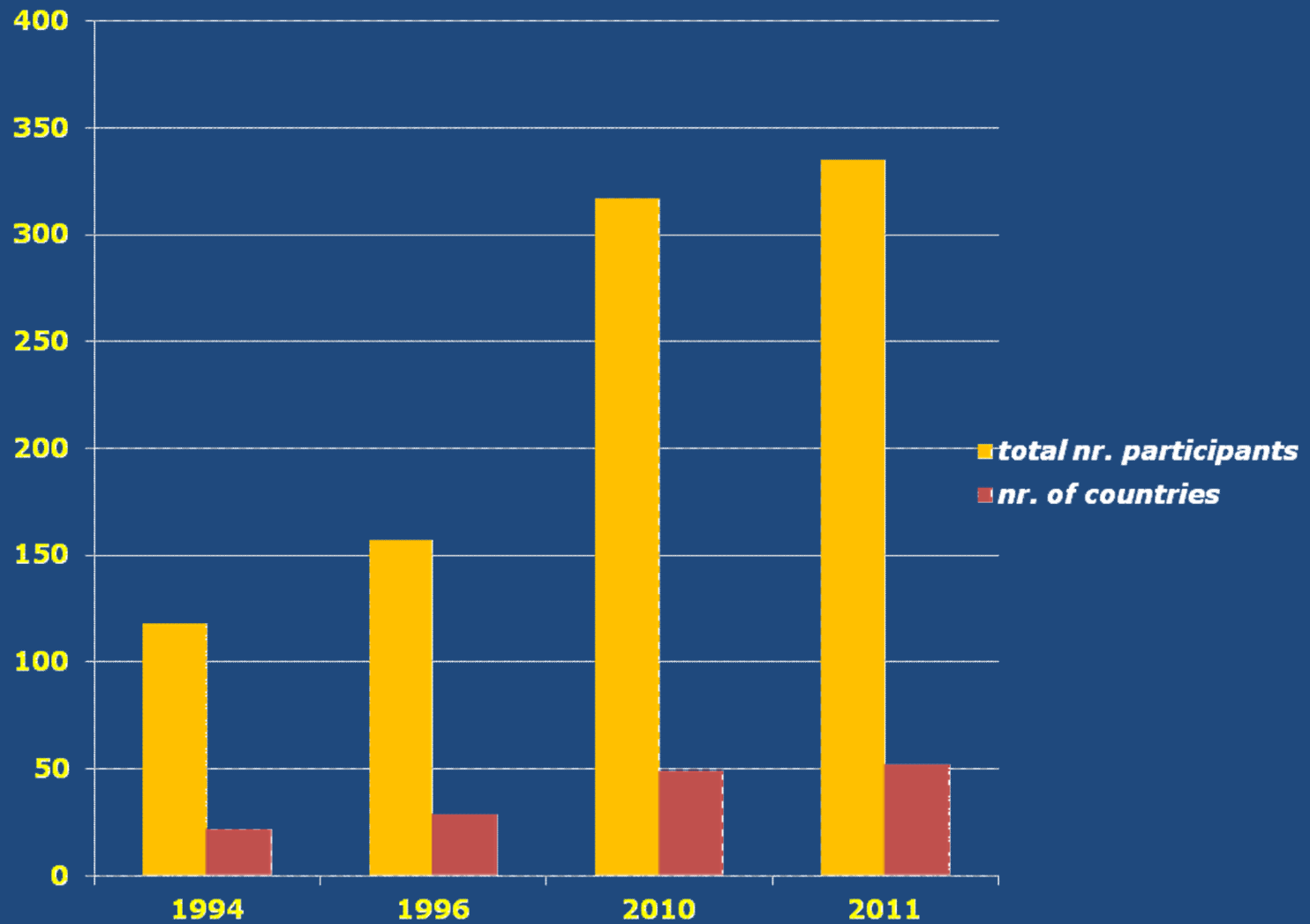
## Aims:

- Improvement of quality of management and provision of genetic laboratory services
- Improvement of international exchange of information on validation of genetic testing
- Laboratory accreditation to be considered as the norm.



# What did we achieve?

## 17 years ERNDIM-QAP



## What did we achieve?

- improving of intra- and inter-laboratory reproducibility of diagnostic metabolite analyses
- improvement of diagnostic efficiency

(Fowler et al JIMD 2008)



## What did we achieve?

- Professionalization of the ERNDIM organization
- Improved websites for qualitative schemes and DPT
- Accreditation of ERNDIM organization is in progress



What did we achieve?





But.....Enduring questions

Do we still know why  
we should control the quality of our  
analytical data?

**no number is safer than a false number!!**

Medical action based on false data is more dangerous  
than medical action without certain data



Did we reach our goal?

We have achieved a lot of improvements

but

ERNDIM should continue because quality never ends





Brian,

Thank you for years of friendly co-operation

Enjoy your pension in good health,

Enjoy the freedom of retirement

Enjoy Fc. Basel!!

For their help I want to thank

Anny Brown, Sara Gardner and Jim Bonham

