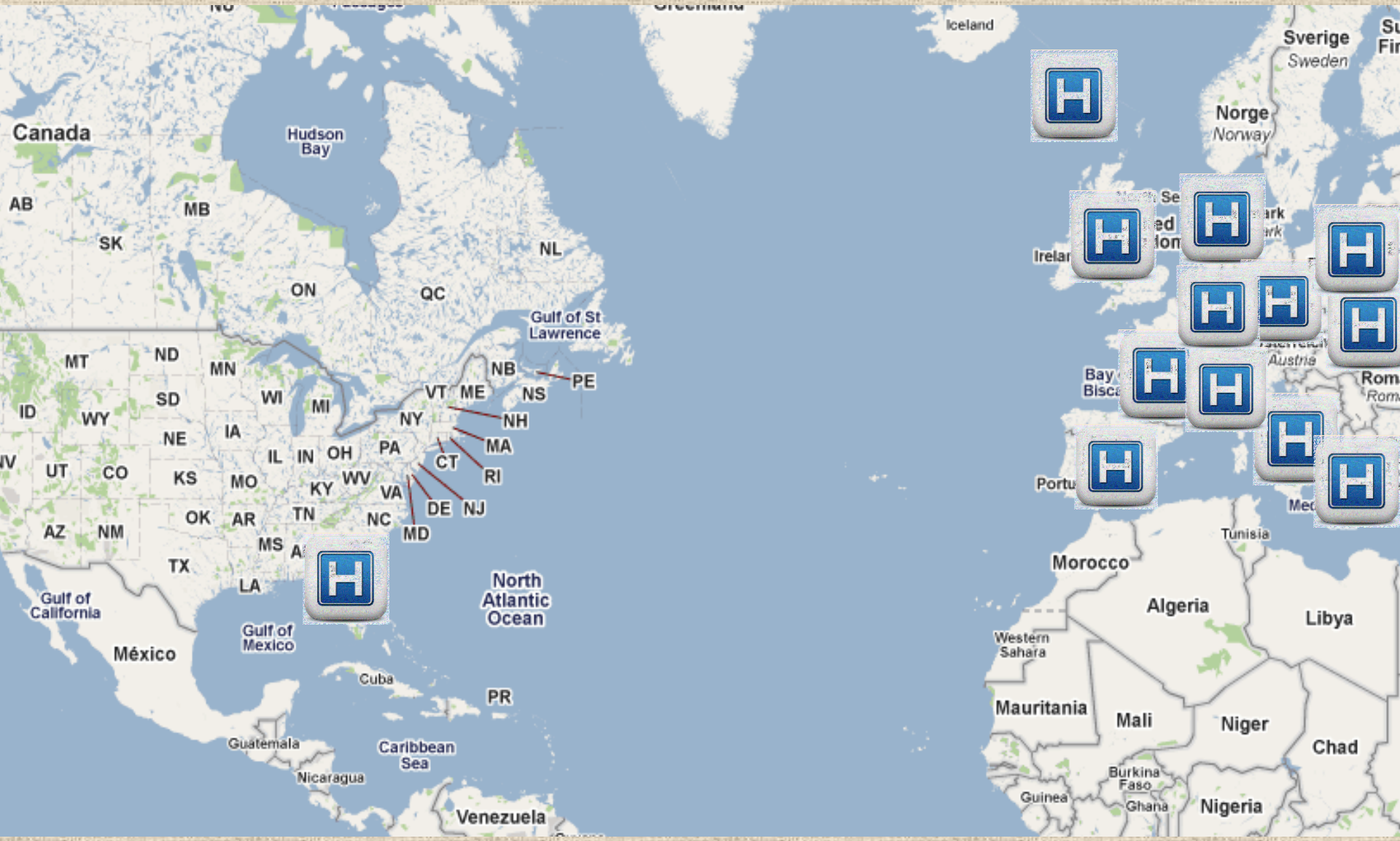
Collaboration

- Extend Databases GSD I and GSD III
- Update Guidelines follow-up and therapy
- Initiate new Collaborative studies
- Expand Databases with tissue samples

ISGSD I/III Network

- Austria
- Belgium
- Canada
- Czech Republik
- Faroër Islands
- France
- Germany
- Great Britain
- Hungary
- Italy
- Israel
- Poland
- Sweden
- The Netherlands
- Turkey
- USA

GSD I & III network around the world…



VitalHealth Software - Windows Internet Explorer

https://gsd3.vitalhealthsoftware.com

VitalHealth Software

User: Jan Nuyt

Logout

umcg

VitalHealth

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VitalHealth for GSD type III

Add information about your GSD type III-patient

Add new patient Search patients

VitalHealth for GSD type III general menu

Access the database including settings and application management

General menu Administration

Done

Internet

100%

start

3 Microsoft Office ...

2 Internet Explorer

2 Microsoft Office ...

2 Windows Explorer

Document1 - Micros...

14:16

VitalHealth Software - Windows Internet Explorer

https://gsd3.vitalhealthsoftware.com

Google | Uitvoeren | Bladwijzers | 13 geblokkeerd | Spelling controleren | Verzenden naar | Instellingen

web zoeken.. | Favorieten | Spaces

Links | Customize Links

VitalHealth Software

Page | Tools

User: Jan Nuyt | Logout

umcg VitalHealth

Home

New patient

Help

Patient | General info | Symptoms | Diagnosis | Diet & Growth

Hospital: UMC Groningen

Patient retrieval code *: 000042

Initials: (Use 3 initials! 1: first initial of first name, 2 and 3: first two letters of surname/maiden name)

Gender *: Male Female

Disease: GSD type III

Birthyear (yyyy) *:

Finish | Next

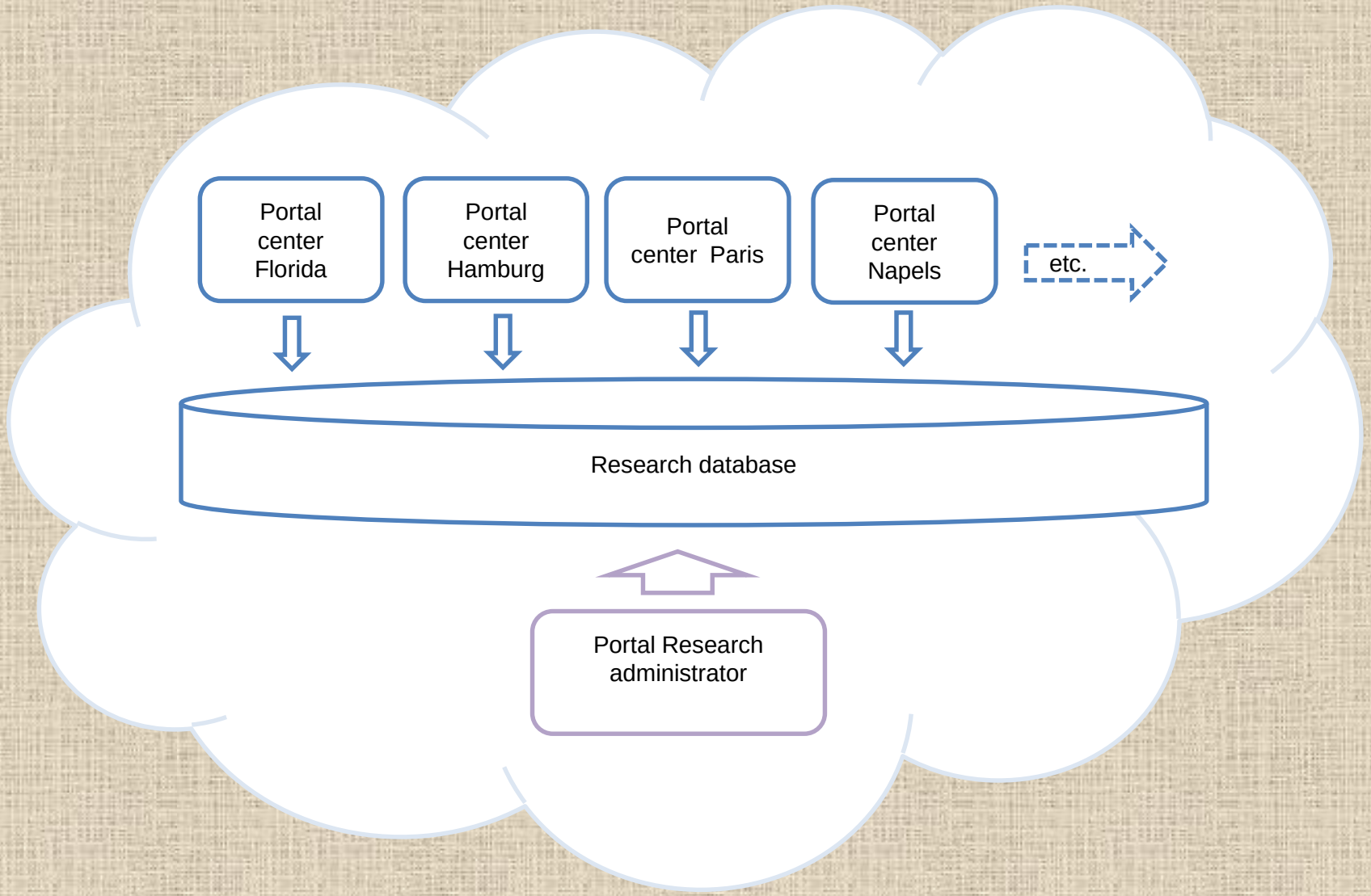
Done | Internet | dinsdag 16 september 2008

start | 4 Microsoft Office... | 2 Internet Explorer | 2 Microsoft Office... | 2 Windows Explorer | Document1 - Micros... | Address | Desktop | 14:17

Characteristics GSD I and III Network

- Combining data from multiple centre in one database
- Registration and follow up per patient, with easy dashboard and notification per e-mail
- Rolebased access, only insight in your “own” patientdata
- Administrator has insight in all (anonymous) data
- Secure webapplication
- Easy to expand with new participants, questionnaires and research studies

GSD I and III combined Database



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- liver kidney muscle fibroblasts DNA

UNIVERSITAIR MEDISCH CENTRUM GRONINGEN

ESGSD I ISGSD I spin-off:

- Uniek netwerk verbonden door GSD-Intranet
- Dissertaties G.Visser, J.P.Rake, D.H.J.Martens 2008
- ISGSD III studie C.P.Sentner
- Richtlijnen voor behandeling en follow-up
- Conferentie Manchester 2008 aanpassing richtlijnen
- EU FP7 aanvraag

Example