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EU Joint Programme – Neurodegenerative Disease Research

Joint Programming in Research

A Pilote Initiative on Combating Neurodegenerative Diseases, in particular Alzheimer's disease

Prof. Thomas Gasser

Chair

Scientific Advisory Board of JPND

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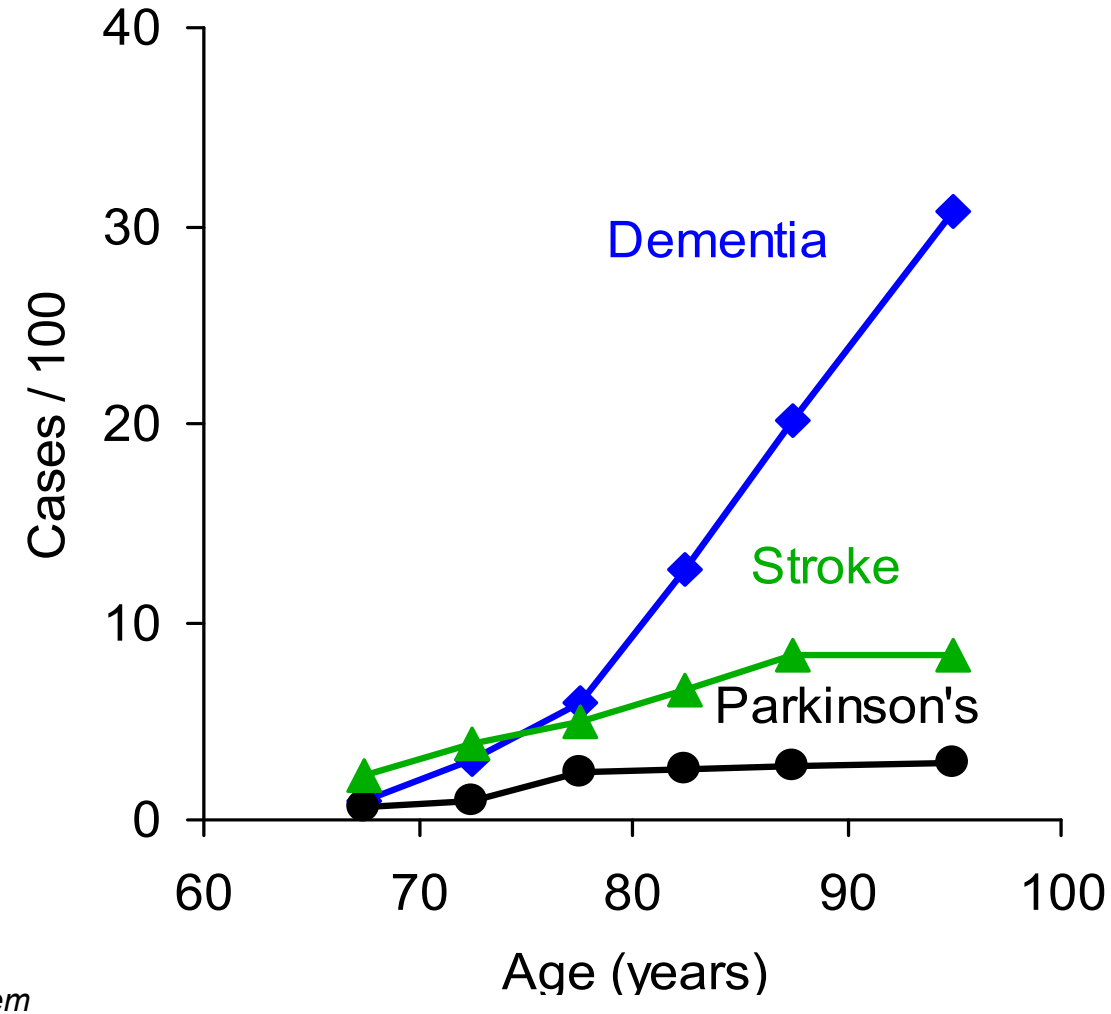
A major societal challenge for the coming years



From Rocca W et al, Eurodem

JP, a Member States and Associated Countries initiative

- 23 Member States and associated countries engaged
  - voluntarily and on a variable geometry basis to tackle neurodegenerative diseases and Alzheimer's in particular
  - in the definition, development and implementation of common strategic research agenda (SRA)

- It entails putting national resources together,
- selecting or developing the most appropriate instrument(s)
- collectively monitoring and reviewing progress.

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23 Participants

- Albania
- Belgium
- Czech Republic
- Denmark
- Finland
- France
- Germany
- Greece
- Hungary
- Ireland
- Italy
- Luxemburg
- The Netherlands
- Norway
- Poland
- Portugal
- Slovak Republic
- Slovenia
- Spain
- Sweden
- Switzerland
- Turkey
- United Kingdom

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A Management Structure

- **Funded by a Coordiation Action in FP7 (JUMPahead)**
- **A Management Board**
  - ➔ Chair : Philippe Amouyel, **France**
  - ➔ Vice Chair : Maria Wästfelt, **Sweden**
  - ➔ **Representatives of all participating states**
- **An Executive Board**
  - ➔ Chair : Philippe Amouyel, **France**
  - ➔ Vice Chair : Maria Wästfelt, **Sweden**
  - ➔ members : Adriana Maggi, **Italy** ; Enda Connolly, **Ireland**; Eckhart Curtius, **Germany**
- **A Scientific Advisory Board (15 scientists)**
  - ➔ Chair : Thomas Gasser, **Germany**
  - ➔ Vice Chair : Martin Rossor, **UK**

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The JUMPAHEAD Work Plan

- **Objectives**
  - Mapping of National and European research programmes
  - Definition of strategic and scientific priorities that would benefit from coordination at the European level (Strategic research agenda)
  - Identification of framework conditions, i.e. political, legal, regulatory and financial arrangements
  - Engagement of stakeholders through a communication plan to ensure translation into practice and policy
  - Evaluation and monitoring of the joint activities

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The Scientific Advisory Board

- **Basic research**

  John Hardy (UK)
  Thomas Gasser (D)
  Jesus Avila de Grado (S)
  Bart de Strooper (B)
  Leszek Kaczmarek (PL)

- **Clinical research**

  Bengt Winblad (SW)
  Martin Rossor (UK)
  Philip Scheltens (NL)
  Bruno Dubois (F)
  Stefano Cappa (I)

- **Main missions:**
- **To help designing the SRA**
- **To suggest the first priorities to support**

- **Health Care and Social research**

  Laura Fratiglioni (SW)
  Henry Brodaty (Australia)
  Martin Knapp (UK)
  Jesus de Pedro Cuestas (S)
  Myrra Vernooij-Dassen (NL)

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Building the Strategic Research Agenda

- **Mapping** the research field at National and European levels
- **Identify research priorities** through a series of workshops (**bottom-up strategy)**
- Identify the **gaps to bridge**
- Organize a list of **priorities to implement**

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SAB workplan

- **Workshops will be organized by the SAB to prepare the SRA in March and April**
- **Three one day thematic workshops**
  - ➔ Basic Research (Madrid)
  - ➔ Clinical Research (Paris)
  - ➔ Social Healthcare (London)
- **One two day final workshop**
  - ➔ With stakeholders the first day
  - ➔ SAB the second day

- **The SRA will be open to "public" discussion through a web consultation**
- **The SRA will be adopted during the second half of 2011**

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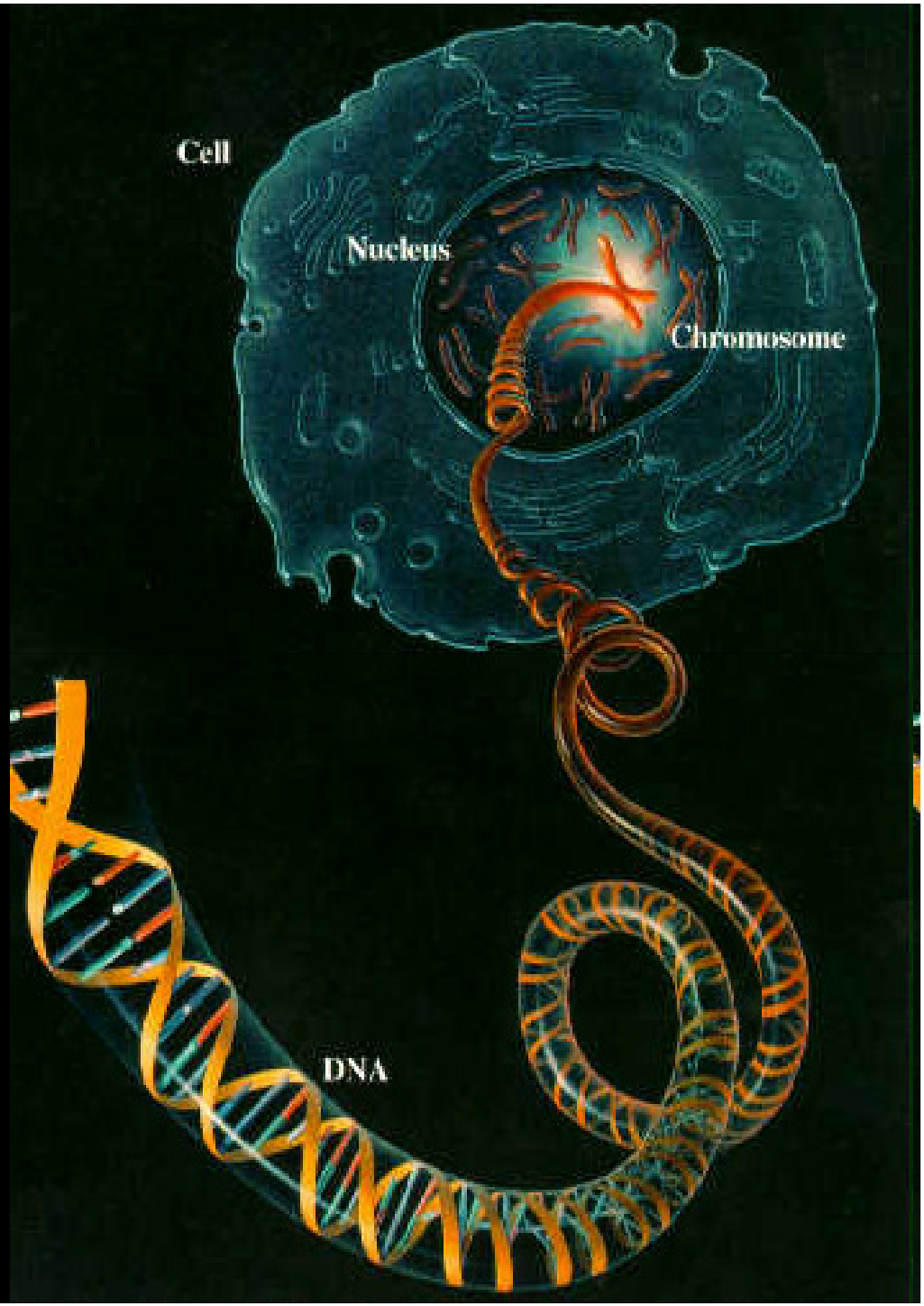
Strategic Research Agenda: challenges and opportunities in Neurodegenerative Diseases

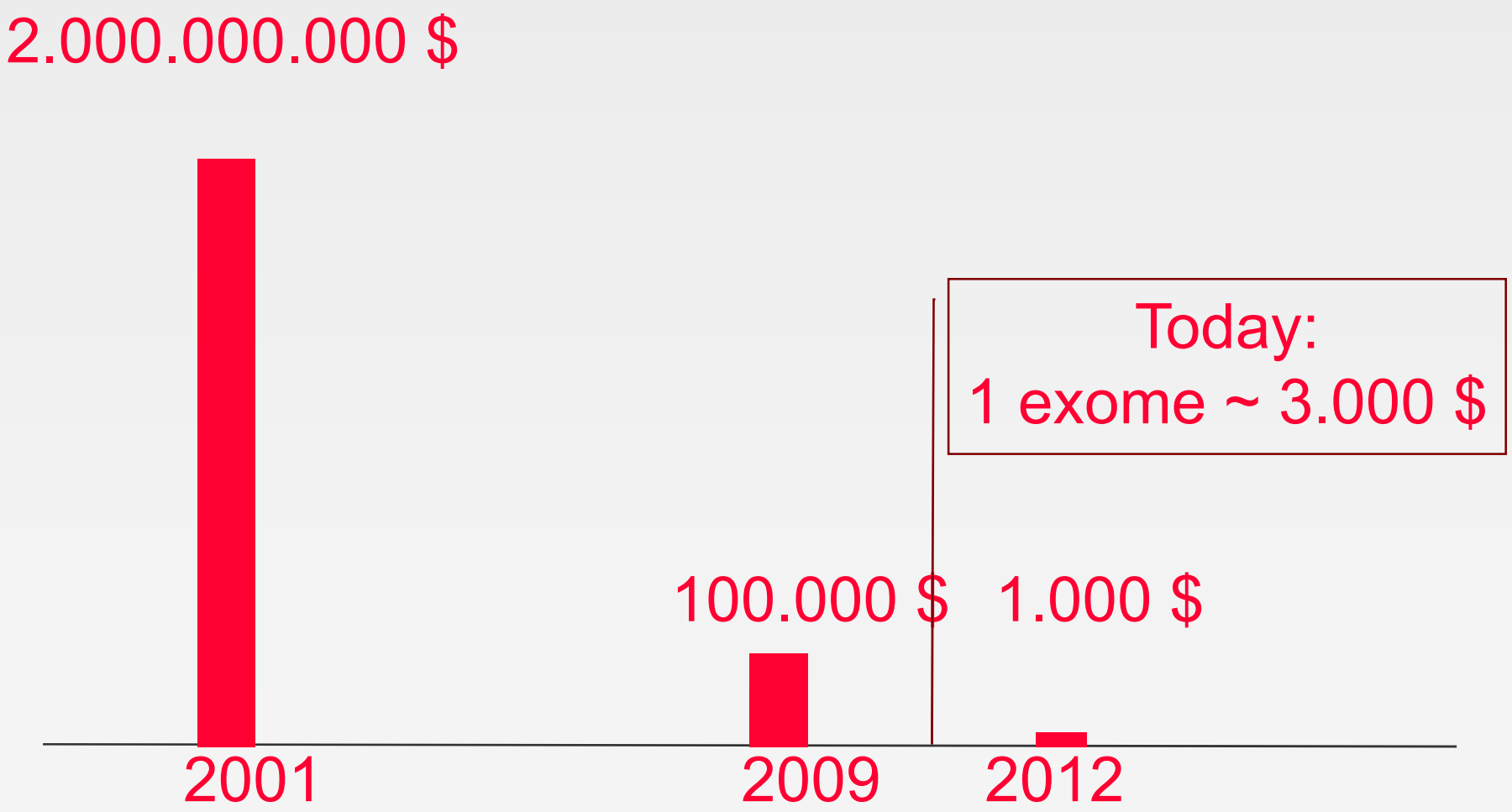

Science
THE HUMAN GENOME

The human genome

- 3 billion base pairs
- 22 autosome pairs, XY
- ~ 22.000 genes
- ~ 180.000 exons



Sequencing Costs Whole Genome (3.000.000.000 bp)



Celebrity genomes alarm researchers

Genome researchers are questioning the plans of some of their number to stage high-profile releases of their very own genome sequences.

Tension over the issue surfaced this month at the annual genomics meeting at Cold Spring Harbor Laboratory in New York. There, some researchers expressed concerns that sequencing prominent scientists first will make personal genomics look like a tool for the rich and privileged.

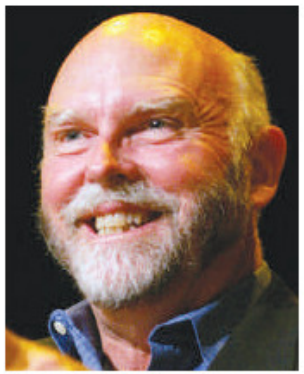
At the meeting, Michael Egholm, a vice-president at 454 Life Sciences, a sequencing technology company in Branford, Connecticut, stood by a poster describing his company's effort to sequence the genome of genetics pioneer James Watson. The company claims this is the first sequence of an individual human genome, and that it took three months and cost about $1 million. "So, is this [illegible]" joked a scientist inspe[illegible]

Egholm winced a[illegible]

are uncomfortable with that.

"If all the sequences obtained over the next year or two are done on scientists with strong financial positions, that will send a message quite contrary to what the genome project aimed to achieve," says Francis Collins, head of the US National Human Genome Research Institute (NHGRI) in Bethesda, Maryland.

The sequencing of individual human



The sequenced: (from left) James Watson, Craig Venter, George Church.

Two individuals differ in ~ 3.000.000 bp

of his genome will be described in an upcoming paper in the journal *PLoS Biology*.

Next up will probably be sequencing guru George Church of Harvard University, who is one of the first ten volunteers for his privately funded Personal Genome Project. Then there is the Archon X Prize in Genomics — a $10-million cash award for the first team to sequence 100 genomes in 10 days — for which Venter is co-chair of the scientific advisory board. The prizewinner can claim a $1-million bonus by sequencing a list of 100 individuals, including people nominated by disease advocacy groups, and celebrities such as television journalist Larry King, cosmologist Stephen Hawking, Google co-founder Larry Page, Microsoft co-founder Paul Allen and former junk-bond trader Michael Milken.

[illegible] researchers won- [illegible] will see personal [illegible] for the benefit of [illegible]

Genetics of complex diseases

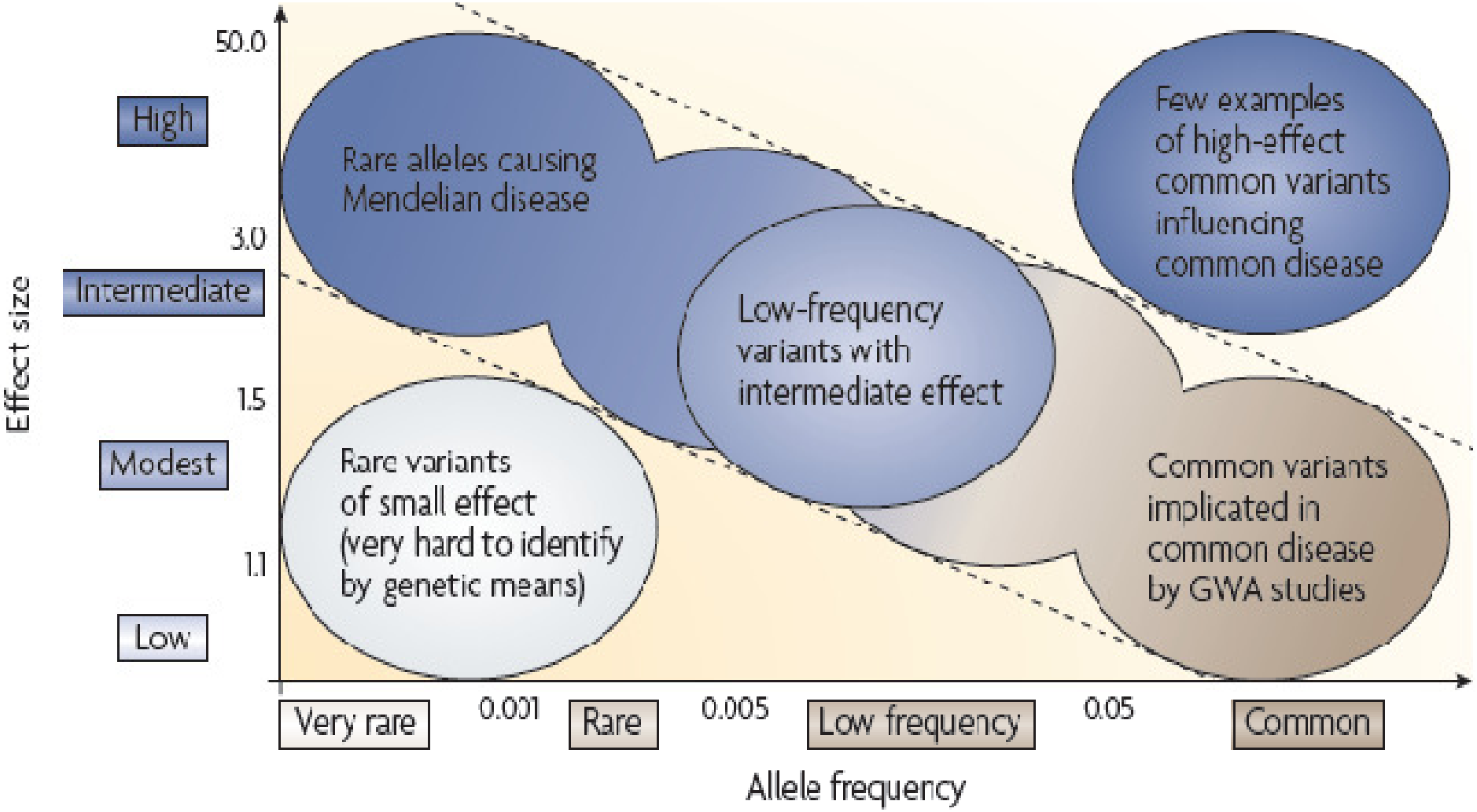


Figure 1 | **of geneti** **ngth** (2009)

20 to 40% of disease risk explained

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SRA: challenges and opportunities

- **1. Causes:** Genetics will remain the important "entry point
- **2. Pathomechanism:** Transcriptomic, proteomic and metabolomic networks ("systems biology")
- **3. Biomarkers:** for early (presymptomatic) diagnosis and disease progression
- **4. Model systems**
- **5. Patient cohorts** A clinical study infrastructure,

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SAB/SC proposals

- **Pilot Initiatives:**
  - **„Urgent proposals"**
  - **„Centers of Excellence Network" (COEN)**

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SAB/SC proposals

- **„Urgent proposals"**
  - **During its first meeting the SAB proposed an urgent topic to be implemented as soon as possible:**

"Harmonization determination of CSF-biomarkers for Neuro-degeneration across Europe"

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SAB/SC proposals

- **„Centers of Excellence Network" (COEN)**
  - launched on June 10 by the MRC, the Canadian Institute of Health Research (CIHR) and Deutsches Zentrum für Neurodegenerative Erkrankungen (DZNE), recently joined by Belgium, Italy and Ireland
  - Total 5 Million € for coordinated research
  - 3 workshops to identify research priorities
    - Imaging
    - Animal Models
    - Biomarkers
  - Adopted as a JPND measure by MB on Oct 22

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Problems

- no common pot

- Bottom up vs. Top down

- education