

Open access to Telethon publications in the framework of Europe PubMed Central



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TELETHON OVERVIEW

- The Telethon Foundation is a **major Italian charity** focused on **rare genetic diseases**
- **Founded in 1990**, it relies on **donations** from the general public

MISSION

To advance biomedical research towards the cure of rare genetic diseases, otherwise neglected by major public and private investments

➤ The ultimate goal is **to make therapies available** to all **patients** in need

Research Spend: 25,1 Million €/Year
(Average 2010-2012)

RESEARCH GRANTS

to Italian non-profit research institutes

- **Research Projects** ~40/yr
- **Clinical NMD Projects** ~ 4/yr
- **Exploratory Projects** ~ 10/yr
- **Biobank Network**: 10 active

Peer
Review

INTRAMURAL RESEARCH

- **TIGEM** - Telethon Institute of Genetics and Medicine, Naples (170 people)
- **HSR-TIGET** - HSR-Telethon Institute of Gene Therapy, Milan (110 people)
- **DTI** - Dulbecco Telethon Institute (Career program), 19 labs (140 people)

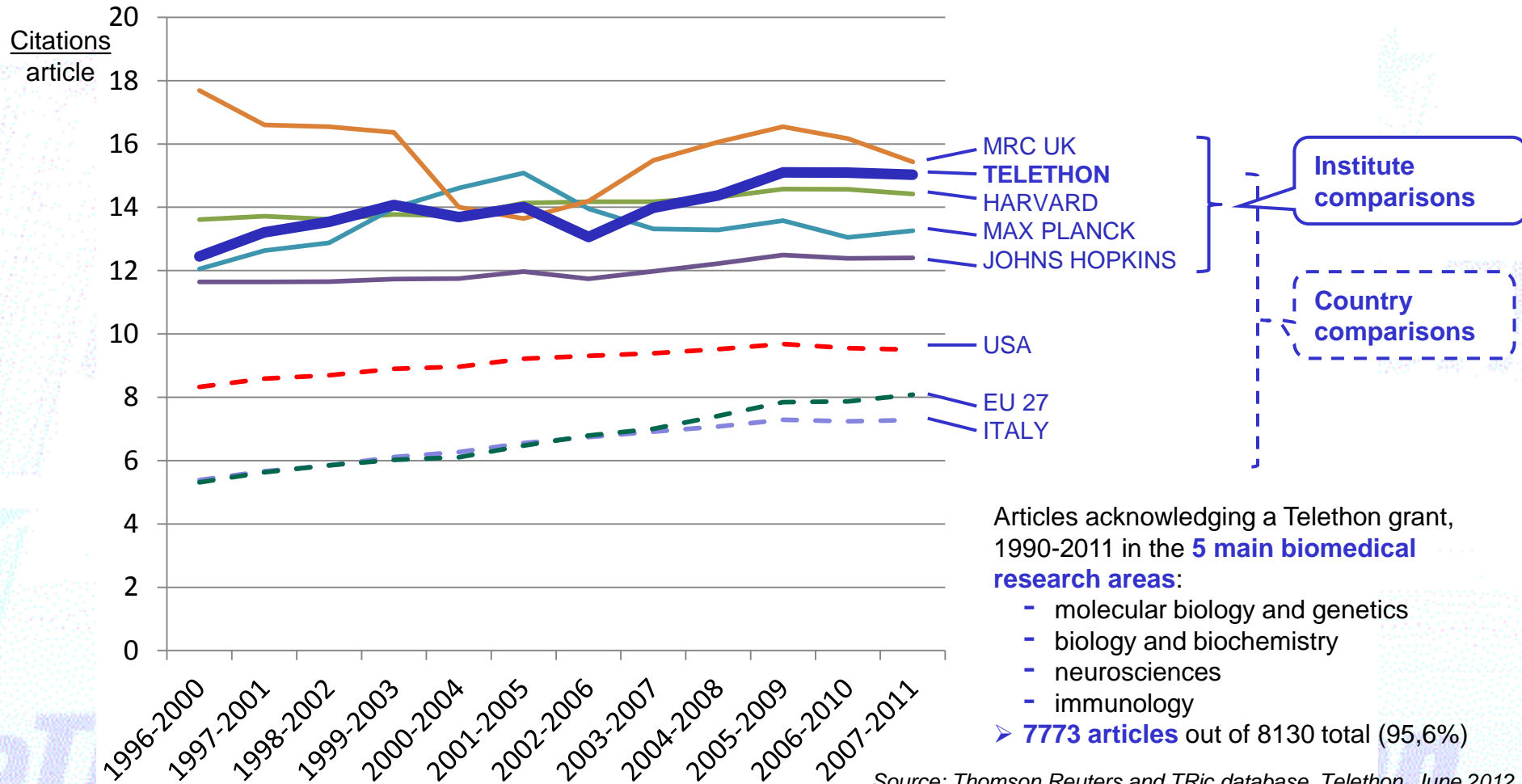
SCIENTIFIC ARTICLES: THE FIRST OUTPUT OF TELETHON RESEARCH

8487 articles by Telethon-funded investigators in 1991-2011

84% original articles

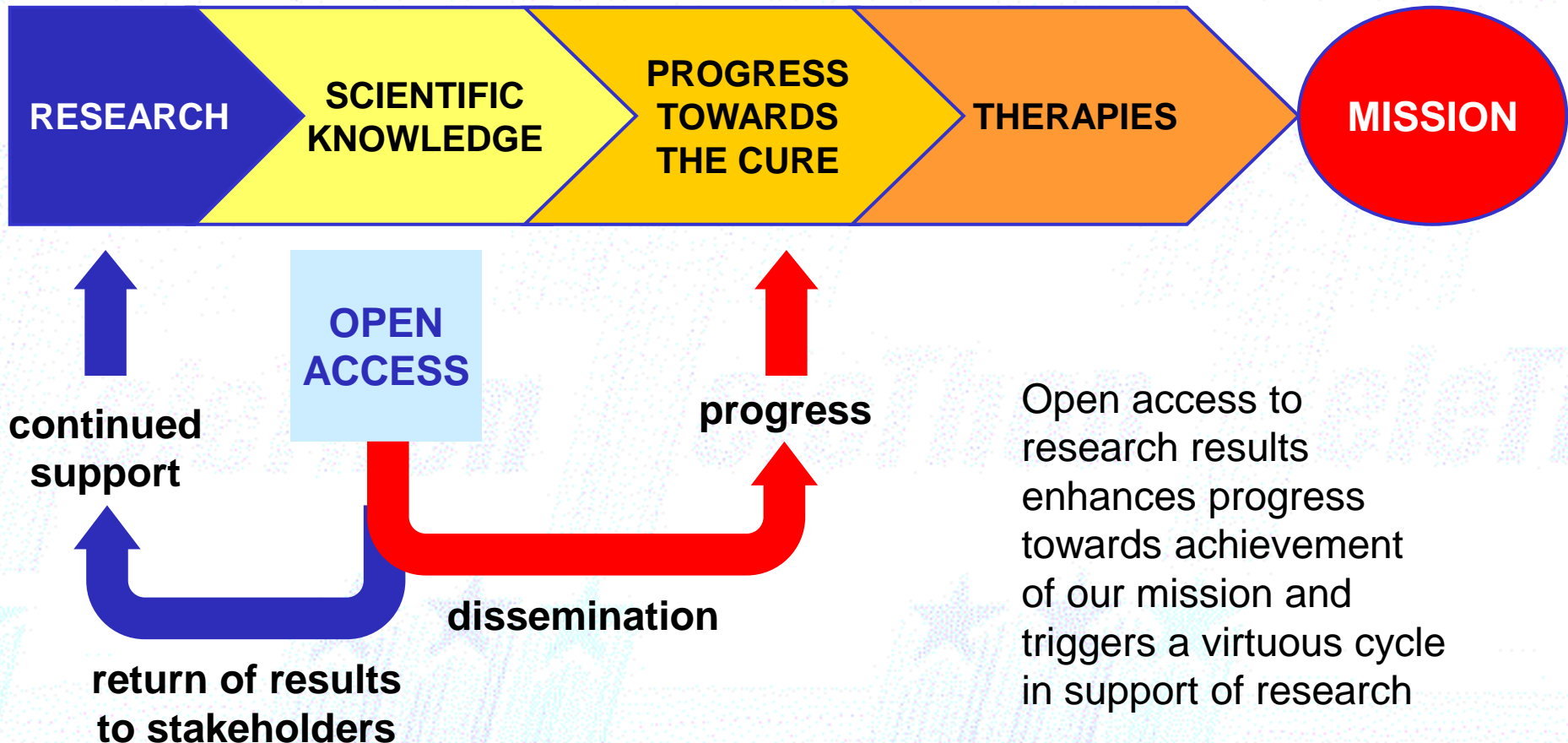
51% authored by a Telethon PI as first/last author *

*underestimated figure due to first/last position co-authorships (not indexed)



Source: Thomson Reuters and TRic database, Telethon, June 2012

WHY SHOULD A BIOMEDICAL CHARITY PROMOTE OPEN ACCESS



TELETHON'S OPEN ACCESS POLICY

- Active since **July 2010** → **Telethon joined UK PubMed Center and is now one of the funders of Europe PubMed Central**
- The policy applies to **original research articles (ORA)**
 - **Maximum 6 months embargo** → free self archive, or
 - **Immediate access** → **OA fees paid by Telethon**
- **Agreements with publishers** (BMC, Plos, Elsevier, Wiley → monthly invoices)
- **OA fee shared** (in principle) with other funders acknowledged in the publication
- **Dedicated resources**
 - Dedicated funds:

2010/11	123 K€ (0.5% research spend) – 6 months
2011/12	335 K€ (1.3% research spend) – full year
2012/13	450 K€ (1.8% research spend) – allocated
 - Direct management: 4 people (2 from the Scientific Office + 2 from the Administrative Office) = **1 FTE** for:
 - relationships with scientists and publishers
 - Database of publications
 - pre- and post publication controls
 - administrative processes



Europe PMC is based on PubMed Central (PMC), developed at the NCBI in the USA and is part of a network of PMC International (PMCI) repositories that also includes PMC Canada.

Europe PMC is developed by the European Bioinformatics Institute, The University of Manchester (Mimas and NaCTeM), and the British Library.

Services

- **Free access to full text of peer-reviewed published journal articles**, PubMed abstracts and **other contents**, such as **biological patents, clinical guidelines**, PhD theses and research reports,
- grant information (*Grant reporting System*) for funders and for grantees
- **advanced text mining system** (e.g. search for Biological Terms, Related Citations and Bioentities).

Support

- **19 funders** of biomedical research, including charities and government organisations in the UK, Austria, and Italy

The funders require that **research papers** be made **freely available** via Europe PMC **no later than 6 months** after publication (**Europe PMC+** manuscript submission system)

TELETHON'S OPEN ACCESS MANAGEMENT

Set up

- **Publishers** informed of the Telethon policy
- Ad hoc **agreements** with key publishers to manage OA workflow, including payments
Examples: monthly payments, prepaid accounts, deposition service (free with NPG)
- **Database** of Telethon publications implemented to include all OA information

Workflow

- PI contacts Telethon about his/her publication, or
Publisher recognizes a Telethon funded articles and contacts Telethon
- Telethon checks publication-grant match
- Telethon directly manages payment (if needed) or
Telethon requests the PI to self-archive in Europe PMC
- Telethon checks that article is available in PubMed Central (PMCID) post-publication

TELETHON OPEN ACCESS NUMBERS

- Average No. of Telethon publications/year: **600** (89% ORA)

Year	% ORA with PMCID (as indicator of OA compliance)	% ORA supported by Telethon-OA fees
2011	54%	22%
2012 (up to September)	52%	34%

- Average OA fee/publication: **2400 €** (VAT incl.)
- If 100% of Telethon original research articles funded research were routed through an OA author-pays model: **1.3 M €** (> **5%** of total research spend!)



Sustainability issue

TELETHON OPEN ACCESS SUSTAINABILITY

Reducing OA burden: options?

- **Restrict OA coverage** of costs: Telethon pays only if
 - The Telethon grantee is **first/last/corresponding author** of the publication
 - Less than 2 years elapsed since the grant closure
- **Negotiating cheaper prices/conditions with publishers**
 - Cannot do it alone!
- **Sharing costs** with other funders acknowledged on the paper
 - Involve more funders in support of OA costs

THANK YOU FOR YOUR ATTENTION!

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