

E-Rare - ERA-Net for research programmes on rare diseases



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- ERA-NET for research programs on rare diseases
- Created in 2006 (E-Rare-1), renewed in 2010 (E-Rare-2), at present funded under Horizon 2020 ERA-Net Co-fund: **E-Rare-3 (2014 - 2019)**
- 28 partners from 21 European, Associated and non-European countries (AT, BE, CA, CZ, CH, DE, ES, FI, FR, GR, HU, IT, IL, JP, LT, LV, NL, PL, PT, RO, TR)
- **Objective: coordinate and promote European and international efforts for funding research on rare diseases**
- E-Rare is mentioned in more than half of National Plans for Rare Diseases in Europe



E-RARE-3: BEYOND EUROPE

28 partners in 21 countries



- | | |
|--|--|
|  ANR (France) – <u>Coordination</u> |  Genome Canada (Canada) |
|  AKA (Finland) |  ISCIII (Spain) |
|  ASSR (Italy) |  ISS (Italy) |
|  CIHR (Canada) |  IT MoH (Italy) |
|  CSO/MOH (Israel) |  MEYS (Czech Republic) |
|  DLR/BMBF (Germany) |  NKFIH (Hungary) |
|  DFG (Germany) |  NCBR (Poland) |
|  FCT (Portugal) |  RCL (Lithuania) |
|  FNRS (Belgium) |  SNSF (Switzerland) |
|  FWO (Belgium) |  TUBITAK (Turkey) |
|  FRQS (Canada-Quebec) |  TRI (Japan) |
|  FFG (Austria) |  UEFISCDI (Romania) |
|  FWF (Austria) |  VIAA (Latvia) |
|  GSRT (Greece) |  ZonMw (Netherlands) |

AVERAGE BUDGETS INVESTED IN RD RESEARCH AT NATIONAL LEVEL* (COMPETITIVE CALLS)

Agency	Average national budget/year
ANR (FR)	10 M€
DLR/BMBF (DE)	27 M€
ISCI (ES)	5.8 M€
FNRS (BE)	0.5 - 1 M€
IT-MOH (IT)	30 M€
RER-ASSR (IT)	3 M€
ZonMw (NL)	11 M€
Tubitak (TR)	N/A
FCT (PT)	N/A
FWF (AT)	N/A
GSRT (GR)	0.75 M€
OTKA (HU)	0.2 M€
UEFISCDI (RO)	N/A
VIAA (LT)	N/A
DFG (DE)	As DLR/BMBF
CIHR/GC/FRQS (CA)	≥ 10 M€
SNSF (CH)	8 M€

On average 100 M€ is invested each year in RD research

* Not exhaustive, countries presented in the table belong to the E-Rare consortium



RD COMMUNITY IN DIFFERENT COUNTRIES

TWO MAJOR GROUPS*:

- Well defined, strong community with academic and clinical coverage; supported at national level either through **national plans** or specific funding programmes; existence of spin offs or start ups and clinical trials funding available; access to tools like genetic identification, bioinformatics, omics, etc. (AT, BE, CA, DE, FR, ES, IT, IL, NL, CH)
- Fragmented; no specific approach to RD at national level or national plan in development; lack or limited national registries or longitudinal studies; lack or low access to specific tools (GR, HU, LT, RO, PL, PT, TR)

ADDED VALUE OF E-RARE:

- E-Rare is an international funding programme, gathering partners with different “background”

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E-RARE CALLS: COUNTRY PARTICIPATION

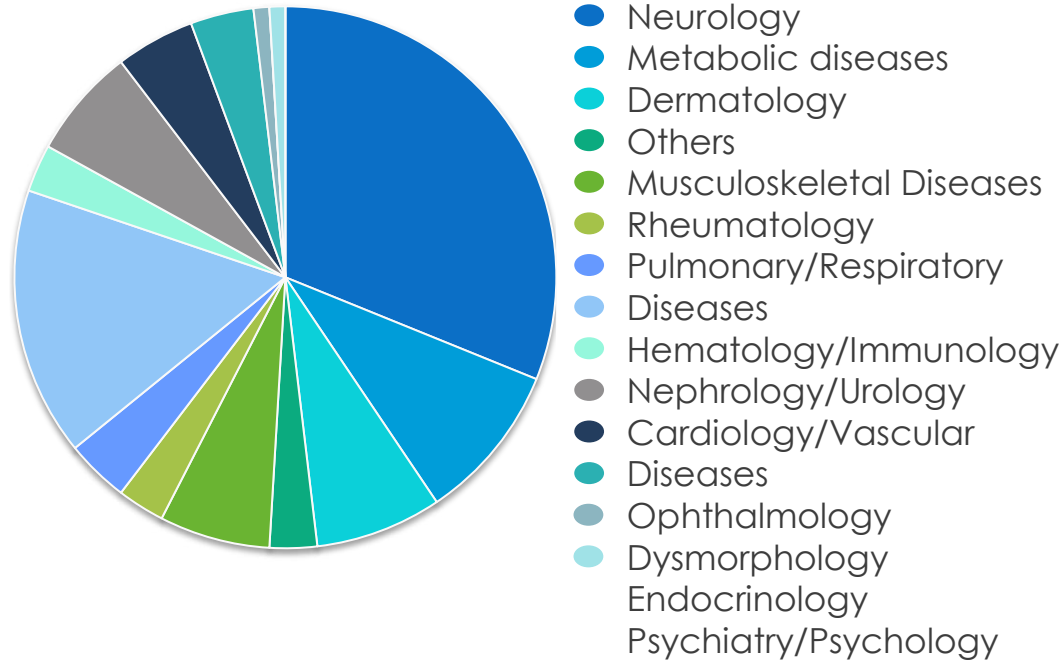
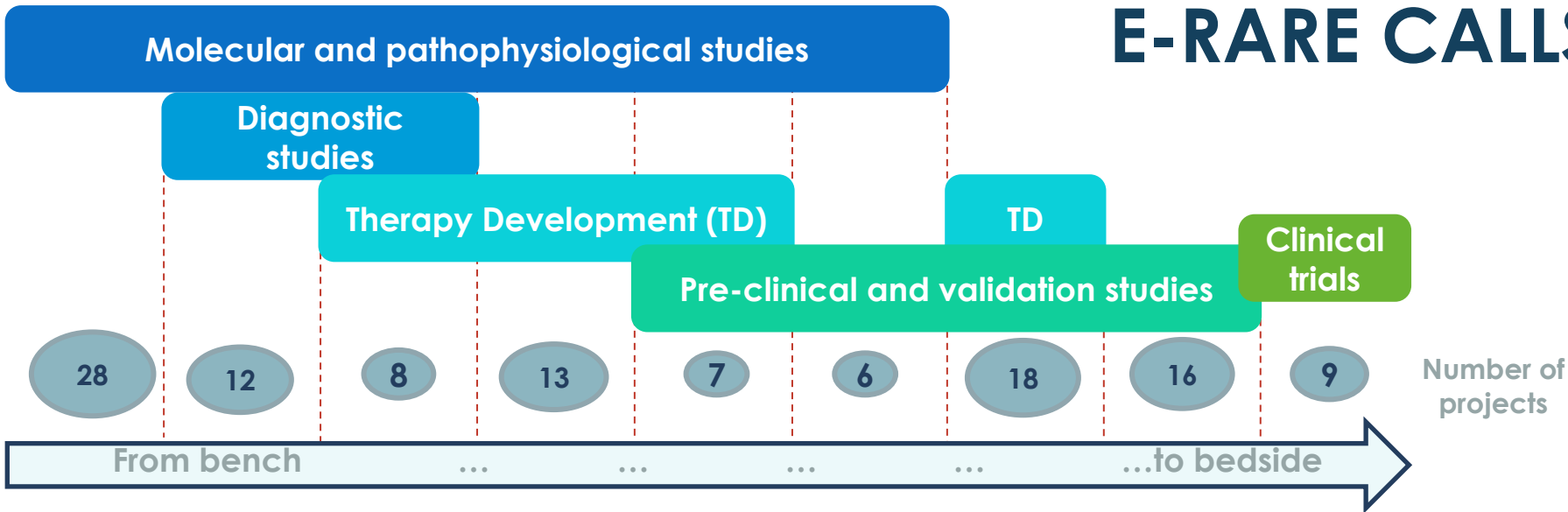


JTC 2007		X	X	X	X	X		X													
JTC 2009		X	X	X	X	X	X	X	X	X	X										
JTC 2011	X/X	X	X	X	X	X		X	X	X											
JTC 2012	X	X	X	X		X	X	X	X		X	X									
JTC 2013	X/X	X	X	X	X	X		X	X		X	X	X/X	X	X/X	X					
JTC 2014	X	X	X	X	X	X	X	X	X		X	X	X/X	X	X	X	X				
JTC 2015	X/X	X/X	X	X	X/X	X	X	X	X/X	X	X	X	X/X/X	X	X	X	X				
JTC 2016	X	X/X	X	X/X	X	X		X	X/X		X	X	X/X/X	X	X	X	X	X			
JTC 2017	X/X	X/X	X	X	X	X/X		X	X	X		X	X/X	X	X	X	X		X	X	
JTC 2018	X/X	X/X	X	X	X	X	X	X	X	X		X	X/X	X	X	X	X			X	X

SPECIFICITY OF E-RARE CALLS:

- Two types of calls: general (open) calls & focused calls (young PIs; novel therapeutic approaches; CTs on repurposing; multi-omics approaches)
- Since 2015 application of “widening approach” → incentives to include teams from Eastern European countries to increase their capacity and knowledge sharing

E-RARE CALLS



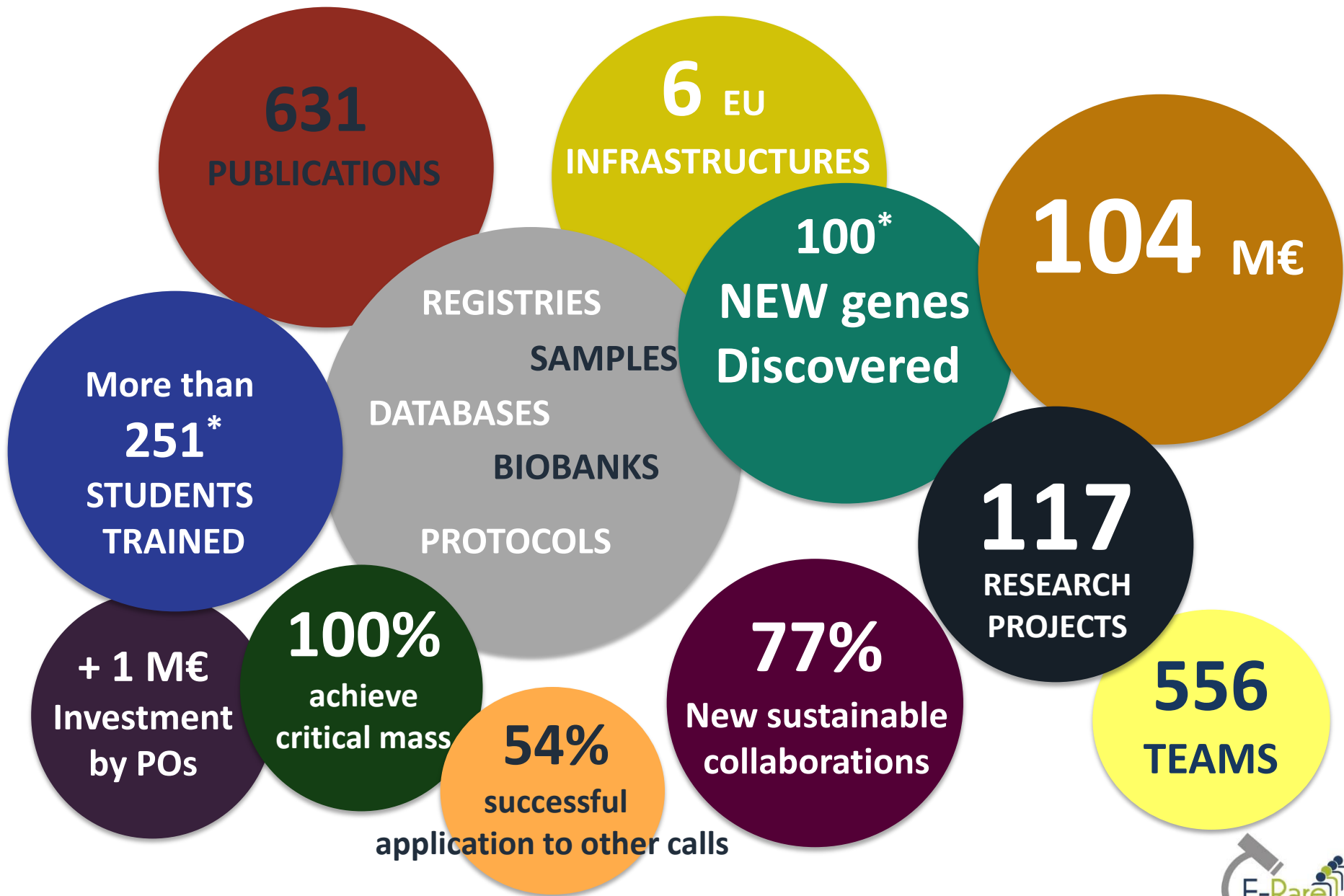
9 Joint Transnational Calls:

117 funded projects

104 M€ invested

Including 556 research partners funded

Medical domains represented in the funded projects



* In 48 finalized projects

Since 2012 is the “E-Rare group of funders” member of the International Rare Diseases Research Consortium (IRDiRC)

- Provides tools for multinational funding mechanisms
- Follows recommendations and guidelines of IRDiRC scientific committees and contributes to IRDiRC’s objectives
- Allows its members to participate in the establishment of IRDiRC’s strategy
- E-Rare coordinator is chair of IRDiRC Funders Constituent Committee



E-RARE, IRDiRC AND THE FUTURE

FUTURE: European Joint Programme on Rare Diseases (EJP RD):

- **Pillar 1:** Research funding (part of E-Rare)
- **Pillar 2:** Coordinated access to data and services
- **Pillar 3:** Capacity building and empowerment
- **Pillar 4:** Accelerating translation
- Close linkage with IRDiRC will be ensured by integration of the IRDiRC Scientific Secretariat in the EJP RD Coordination Office.

