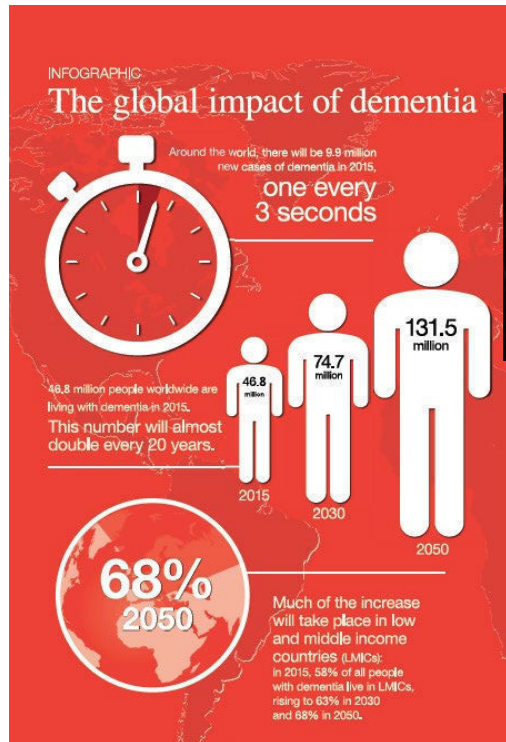


# **State of art neurodegenerative diseases 2008 – 2019 how JPND contributed to it?**

**Thomas Gasser**  
**SAB Chair**  
**University of Tübingen**

# The global threat of neurodegeneration



World dementia report 2015



Alois Alzheimer  
1864-1915

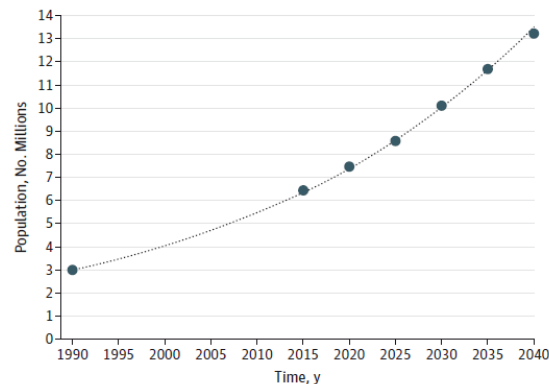
VIEWPOINT

## The Parkinson Pandemic A Call to Action

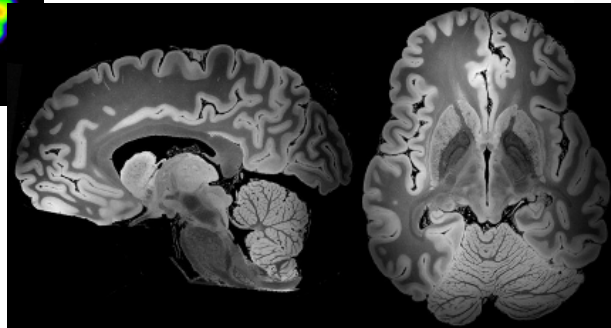
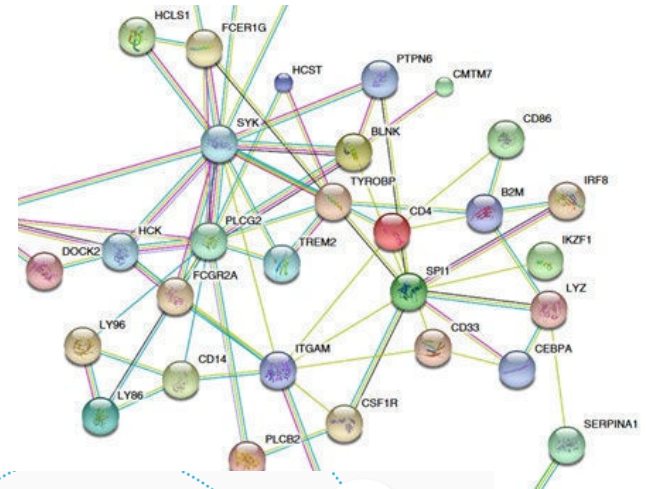
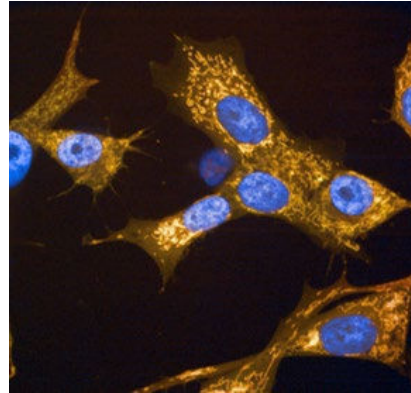
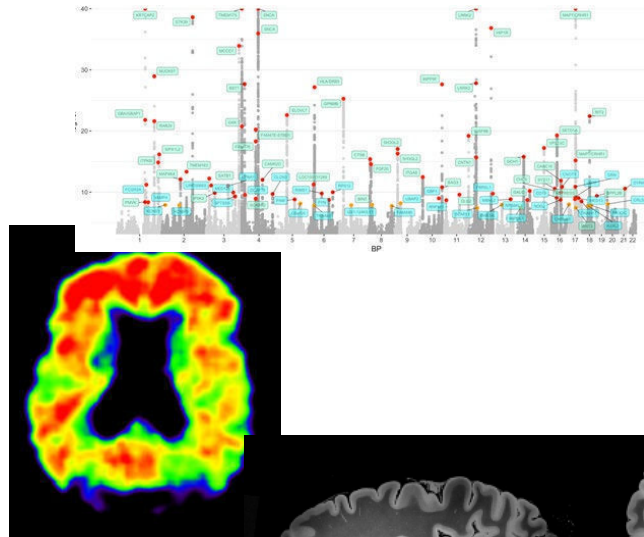
### JAMA Neurology



Figure. Estimated and Projected Number of Individuals With Parkinson Disease, 1990-2040



# Recent progress in neurodegeneration research



# Aligning to defragment: what JPND is all about



## STRATEGIC RESEARCH AND INNOVATION AGENDA



## ALIGNMENT OF COUNTRIES ON COMMON RESEARCH GOALS



# 2010: Scientific Advisory Board



Eyjafjallajökull, eruption on April 14, 2010



## 1. SAB meeting, April 2010





# Delivering the Research Strategy

## Mapping exercise

- Scoping existing research spend and infrastructure (academic)

## Thematic workshops (academia)

- Basic, Clinical and Healthcare themes

## Stakeholder meetings

- Industry
- Patient and carer associations

## Integrating workshop

- SAB and opinion leaders from thematic and stakeholder workshops

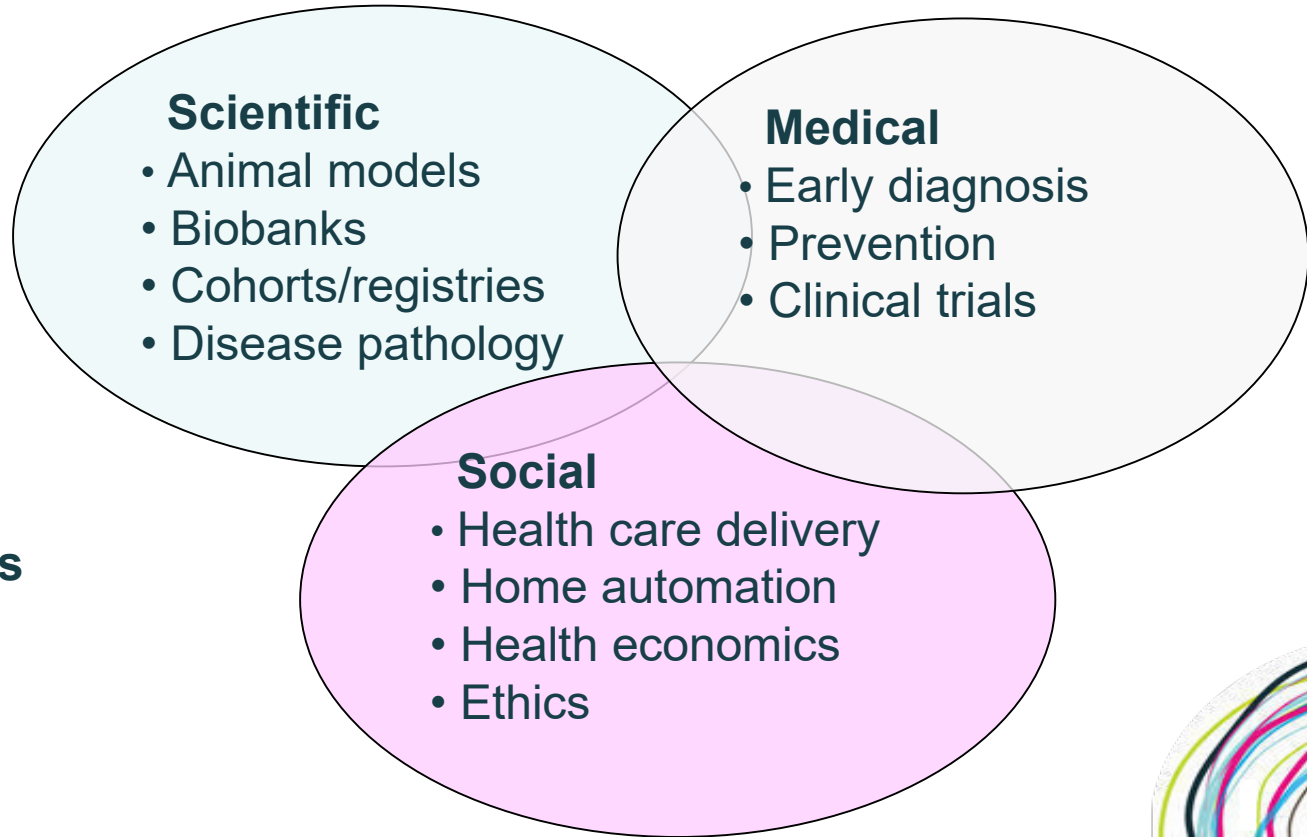
## Consultation

- Public online consultation



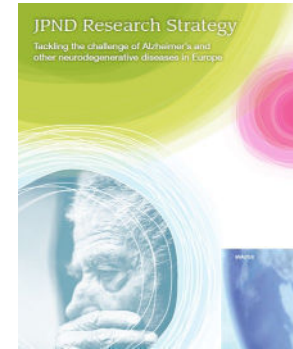
# Scope of the initiative

## Focus on Three Domains



# 2012: The Strategic Research Agenda – thematic priorities

- **Thematic priorities for future research:**
  - The origins of neurodegenerative disease
  - Disease mechanisms and models
  - Disease definitions and diagnosis
  - Developing therapies, preventive strategies and interventions
  - Health and social care





# Evolution of the scientific strategy



2012

2019



# At the JPND level = transnational calls

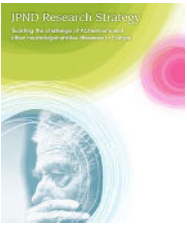
**Total investment  
€152 million**

## Joint Transnational Calls:

- Between 20 and 189 proposals
- Between 122 and 892 teams participating to the call

**124 projects supported**

Center of Excellence Network	Joint Transnational Call	Year	Budget	Research topic	N° of Projects
		2011	€13.6M	Optimisation and harmonisation of biomarkers	4
		2012	€17M	Risk and protective factors	5
		2012	€9.0M	Evaluation of health care policies and interventions	6
		2013	€13M	Cross-disease analysis of pathways	10
		2013	€7M	Preventive strategies: pilot studies	5
		2015	€36M	Risk and protective factors, longitudinal cohort approaches and advanced experimental models	21
		2017	€14.5M	Cross-disease analysis of pathways	10
Center of Excellence Network	Rapid Call	2018	€19M	Health and Social Care research	10
		Year	Budget	Research topic	N° of Projects
		2014	€0.5M	Working Groups to Inform Cohort Studies	10
		2016	€0.5M	Working Groups for Harmonisation and Alignment in Brain Imaging Methods	10
		Year	Budget	Research topic	N° of Projects
		2012	€6 M	Common resources and methodological approaches	8
		2013	€5.8 M	Pathfinder projects	5
		2016	€4.9M	Pathfinder projects	11
		2017	€4.6M	Pathfinder projects	9



# Theme 1: Origins of NDDs



2012: “European research projects for the identification of genetic epigenetic and environmental risk and protective factors for Neurodegenerative Diseases”

2015: “A call for European research projects on neurodegenerative diseases: risk and protective factors, longitudinal cohort approaches and advanced experimental models”



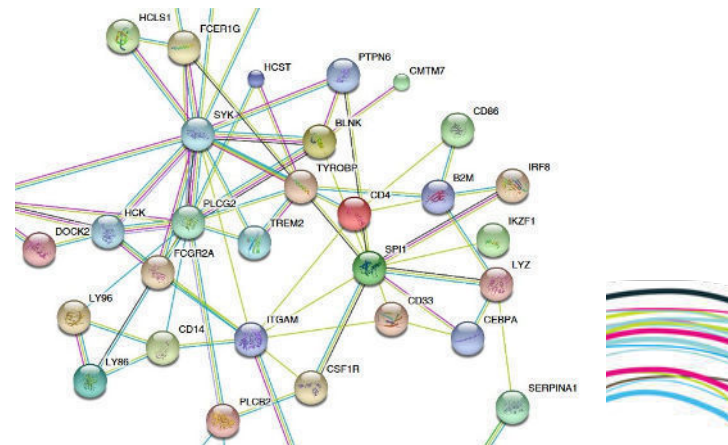
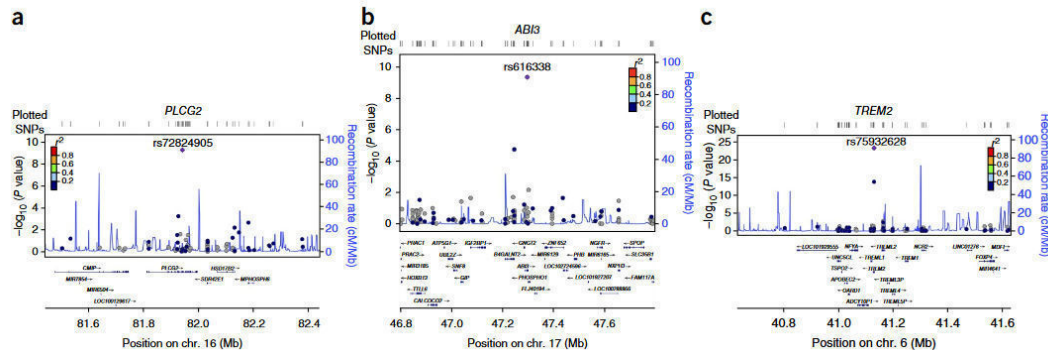


## Defining Genetic, Polygenic and Environmental Risk for Alzheimer's Disease using multiple powerful cohorts, focussed Epigenetics and Stem cell metabolomics

nature  
genetics

## LETTERS

# Rare coding variants in *PLCG2*, *ABI3*, and *TREM2* implicate microglial-mediated innate immunity in Alzheimer's disease



# Theme 1: Origins of NDDs



## COURAGE-PD

Comprehensive Unbiased Risk Factor Assessment  
for Genetics and Environment in Parkinson's Disease

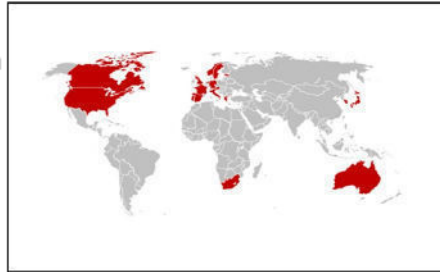


### NeuroChip

Backbone: 306,670 common  
and rare variants

Custom: 179,467 variants

- AD
- PD
- DLB
- ALS
- PSP
- CBD
- MSA

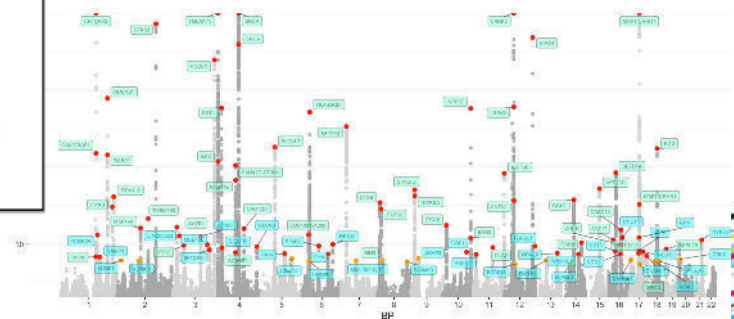


15,849 PD cases and 11,444 healthy  
controls of Asian, Caucasian and African  
ancestry (GWAS study) (WP2)

## Identification of novel risk loci, causal insights, and heritable risk for Parkinson's disease: a meta-analysis of genome-wide association studies

Mike A Nalls<sup>\*</sup>, Cornelis Blauwendraat<sup>\*</sup>, Costanza L Vallerga<sup>\*</sup>, Karl Heilbron<sup>\*</sup>, Sara Bandres-Ciga<sup>\*</sup>, Diana Chang<sup>\*</sup>, Manuela Tan, Demis A Kia, Alastair J Noyce, Angli Xue, Jose Bras, Emily Young, Rainer von Coelln, Javier Simón-Sánchez, Claudia Schulte, Manu Sharma, Lynne Krohn, Lasse Pihlström, Ari Siitonen, Hirotaka Iwaki, Hampton Leonard, Faraz Faghri, J Raphael Gibbs, Dena G Hernandez, Sonja W Scholz, Juan A Botia, Maria Martinez, Jean-Christophe Corvol, Suzanne Lesage, Joseph Jankovic, Lisa M Shulman, Margaret Sutherland, Pentti Tienari, Kari Majamaa, Mathias Toft, Ole A Andreassen, Tushar Bangale, Alexis Brice, Jian Yang, Ziv Gan-Or, Thomas Gasser, Peter Heutink, Joshua M Shulman, Nicholas W Wood, David A Hinds, John A Hardy, Huw R Morris, Jacob Gratten, Peter M Visscher, Robert R Graham, Andrew B Singleton, on behalf of the 23andMe Research Team<sup>†</sup>, System Genomics of Parkinson's Disease Consortium<sup>‡</sup>, and the International Parkinson's Disease Genomics Consortium<sup>†</sup>

[www.thelancet.com/neurology](http://www.thelancet.com/neurology) Vol 18 December 2019



90 PD risk loci

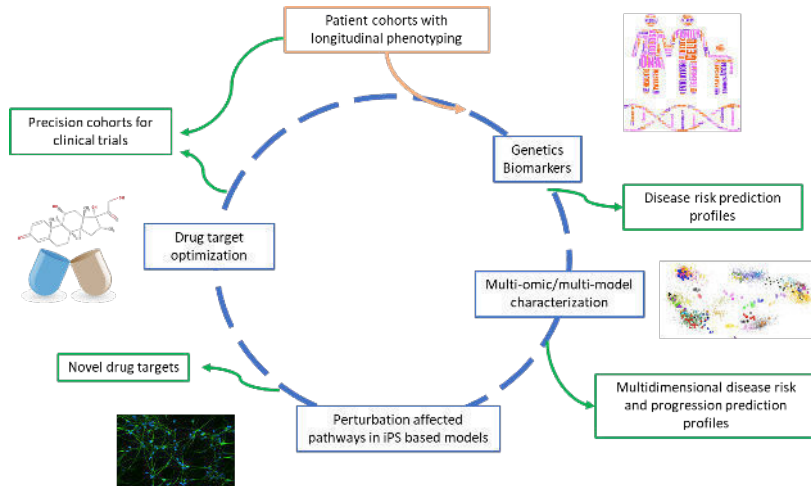


# Theme 1: Origins of NDDs



## RiMod-FTD

Risk and Modifying factors in Fronto-Temporal Dementia

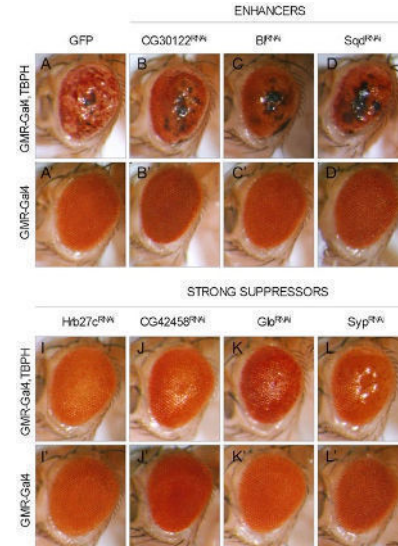


8026–8045 *Nucleic Acids Research*, 2017, Vol. 45, No. 13  
 doi: 10.1093/nar/gkx477

Published online 31 May 2017

## Major hnRNP proteins act as general TDP-43 functional modifiers both in *Drosophila* and human neuronal cells

Chiara Appocher<sup>1,†</sup>, Fatemeh Mohagheghi<sup>1,†</sup>, Sara Cappelli<sup>1</sup>, Cristiana Stuaní<sup>1</sup>, Maurizio Romano<sup>2</sup>, Fabian Feiguin<sup>1,\*</sup> and Emanuele Buratti<sup>1,\*</sup>



## Theme 2: Disease mechanisms and models

2013 JPND Transnational call for “European research projects for Cross-Disease Analysis of Pathways related to Neurodegenerative Diseases”

2015: “A call for European research projects on neurodegenerative diseases: risk and protective factors, longitudinal cohort approaches and advanced experimental models”

2017 JPND call for “Multinational research projects for pathway analysis across neurodegenerative diseases”



# Theme 2: Disease mechanisms and models



## InCure

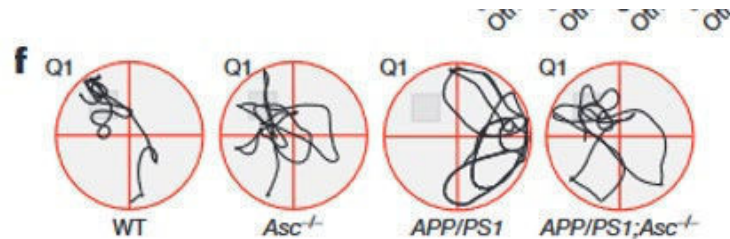
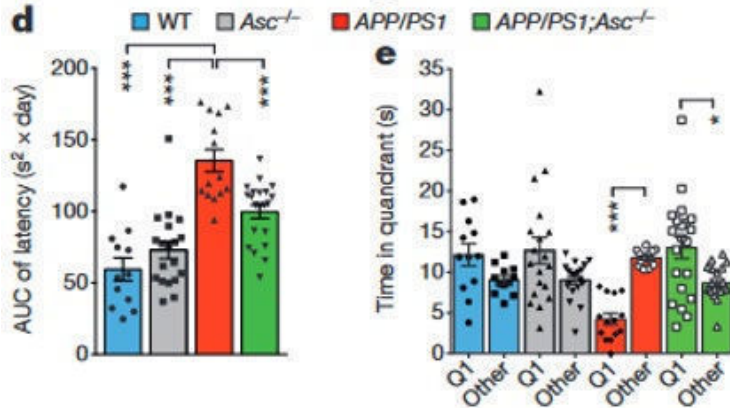
Innate Immune Activation in  
Neurodegenerative Disease

## ARTICLE

doi:10.1038/natu

### Microglia-derived ASC specks cross-seed amyloid- $\beta$ in Alzheimer's disease

Carmen Venegas<sup>1\*</sup>, Sathish Kumar<sup>2\*</sup>, Bernardo S. Franklin<sup>3</sup>, Tobias Dierkes<sup>1,3</sup>, Rebecca Brinkschulte<sup>3</sup>, Dario Tejera<sup>1</sup>, Ana Vieira-Saecker<sup>1</sup>, Stephanie Schwartz<sup>1</sup>, Francesco Santarelli<sup>1</sup>, Markus P. Kummer<sup>1</sup>, Angelika Griep<sup>1</sup>, Ellen Gelpi<sup>4</sup>, Michael Beilharz<sup>1</sup>, Dietmar Riedel<sup>5</sup>, Douglas T. Golenbock<sup>6</sup>, Matthias Geyer<sup>1</sup>, Jochen Walter<sup>7</sup>, Eicke Latz<sup>1,6,7</sup> & Michael T. Heneka<sup>1,6,7</sup>



# Theme 2: Disease mechanisms and models



COORDINATOR | SIMON ALBERTI

## CureALS

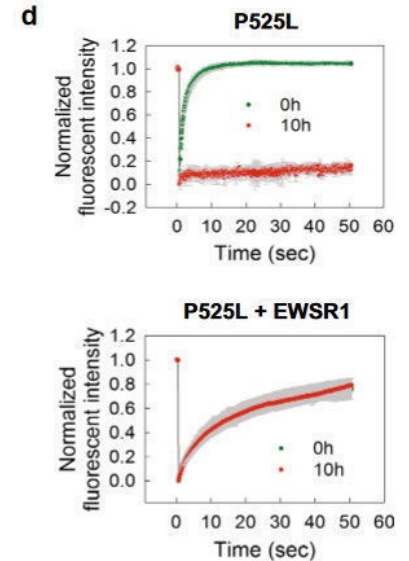
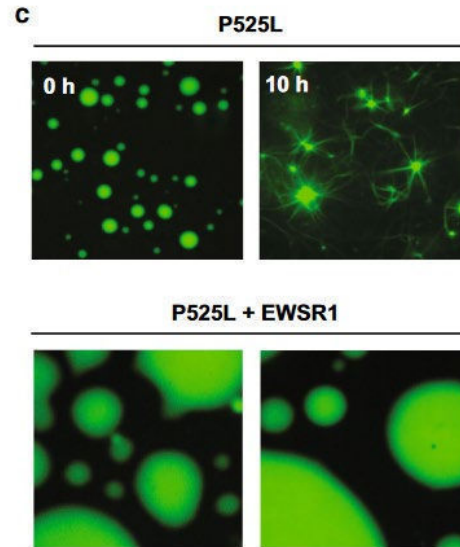
**Stress granules and proteostasis in motor neurons:  
towards a mechanistic understanding of ALS**

Acta Neuropathologica (2019) 138:67–84  
<https://doi.org/10.1007/s00401-019-01998-x>

### ORIGINAL PAPER

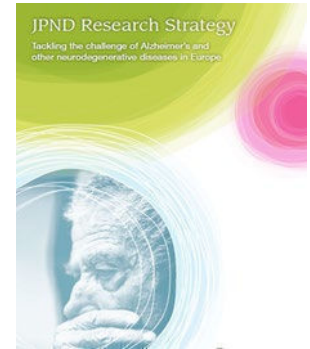
**FUS pathology in ALS is linked to alterations in multiple  
ALS-associated proteins and rescued by drugs stimulating autophagy**

Lara Marrone<sup>1</sup> · Hannes C. A. Drexler<sup>2</sup> · Jie Wang<sup>3</sup> · Priyanka Tripathi<sup>4</sup> · Tania Distler<sup>1</sup> · Patrick Heisterkamp<sup>1</sup> · Eric Nathaniel Anderson<sup>5,6</sup> · Sukhleen Kour<sup>5,6</sup> · Anastasia Moraiti<sup>1</sup> · Shovamayee Maharana<sup>3</sup> · Rajat Bhatnagar<sup>7</sup> · T. Grant Belgard<sup>7,12</sup> · Vadreenath Tripathy<sup>1</sup> · Norman Kalmbach<sup>8</sup> · Zohreh Hosseinzadeh<sup>1</sup> · Valeria Crippa<sup>9</sup> · Masin Abo-Rady<sup>1</sup> · Florian Wegner<sup>8</sup> · Angelo Poletti<sup>9</sup> · Dirk Troost<sup>10</sup> · Eleonora Aronica<sup>10</sup> · Volker Busskamp<sup>1</sup> · Joachim Weiss<sup>4</sup> · Uday Bhan Pandey<sup>5,6,11</sup> · Anthony A. Hyman<sup>3</sup> · Simon Alberti<sup>3</sup> · Anand Goswami<sup>4</sup> · Jared Sternecker<sup>1</sup> 



# Theme 3: Disease Definitions and diagnosis

- 2011 JPND Transnational Call: European research projects for the optimisation of biomarkers and harmonisation of their use between clinical centres”
- 2019: A call for multinational research projects on personalized medicine for neurodegenerative diseases (Co-funded with the European Commission)





# Theme 3: Disease Definitions and diagnosis

PROJECTS SUPPORTED BY JPND



## BIOMARKAPD

Biomarkers for Alzheimer's disease and Parkinson's disease



Alzheimer's & Dementia

Volume 15, Issue 6, June 2019, Pages 742–753



Featured Article

### Longitudinal cerebrospinal fluid biomarker trajectories along the Alzheimer's disease continuum in the BIOMARKAPD study

Alberto Lleó<sup>a, b, c, d, e, f, g, h, i, j, k, l, m, n, o, p, q, r, s, t, u, v, w, x, y, z, aa, ab, ac, ad, ae, af, ag, ah, ai, aj, ak, al, am, an, ao, ap, aq, ar, as, at, au, av, aw, ax, ay, az, ba, bb, bc, bd, be, bf, bg, bh, bi, bj, bk, bl, bm, bn, bo, bp, bq, br, bs, bt, bu, bv, bw, bx, by, bz, ca, cb, cc, cd, ce, cf, cg, ch, ci, cj, ck, cl, cm, cn, co, cp, cq, cr, cs, ct, cu, cv, cw, cx, cy, cz, da, db, dc, dd, de, df, dg, dh, di, dj, dk, dl, dm, dn, do, dp, dq, dr, ds, dt, du, dv, dw, dx, dy, dz, ea, eb, ec, ed, ee, ef, eg, eh, ei, ej, ek, el, em, en, eo, ep, eq, er, es, et, eu, ev, ew, ex, ey, ez, fa, fb, fc, fd, fe, ff, fg, fh, fi, fj, fk, fl, fm, fn, fo, fp, fq, fr, fs, ft, fu, fv, fw, fx, fy, fz, ga, gb, gc, gd, ge, gf, gg, gh, gi, gj, gk, gl, gm, gn, go, gp, gq, gr, gs, gt, gu, gv, gw, gx, gy, gz, ha, hb, hc, hd, he, hf, hg, hh, hi, hj, hk, hl, hm, hn, ho, hp, hq, hr, hs, ht, hu, hv, hw, hx, hy, hz, ia, ib, ic, id, ie, if, ig, ih, ii, ij, ik, il, im, in, io, ip, iq, ir, is, it, iu, iv, iw, ix, iy, iz, ja, jb, jc, jd, je, jf, jg, jh, ji, jj, jk, jl, jm, jn, jo, jp, jq, jr, js, jt, ju, jv, jw, jx, jy, jz, ka, kb, kc, kd, ke, kf, kg, kh, ki, kj, kk, kl, km, kn, ko, kp, kq, kr, ks, kt, ku, kv, kw, kx, ky, kz, la, lb, lc, ld, le, lf, lg, lh, li, lj, lk, ll, lm, ln, lo, lp, lq, lr, ls, lt, lu, lv, lw, lx, ly, lz, ma, mb, mc, md, me, mf, mg, mh, mi, mj, mk, ml, mm, mn, mo, mp, mq, mr, ms, mt, mu, mv, mw, mx, my, mz, na, nb, nc, nd, ne, nf, ng, nh, ni, nj, nk, nl, nm, nn, no, np, nq, nr, ns, nt, nu, nv, nw, nx, ny, nz, oa, ob, oc, od, oe, of, og, oh, oi, oj, ok, ol, om, on, oo, op, oq, or, os, ot, ou, ov, ow, ox, oy, oz, pa, pb, pc, pd, pe, pf, pg, ph, pi, pj, pk, pl, pm, pn, po, pp, pq, pr, ps, pt, pu, pv, pw, px, py, pz, qa, qb, qc, qd, qe, qf, qg, qh, qi, qj, qk, ql, qm, qn, qo, qp, qq, qr, qs, qt, qu, qv, qw, qx, qy, qz, ra, rb, rc, rd, re, rf, rg, rh, ri, rj, rk, rl, rm, rn, ro, rp, rq, rr, rs, rt, ru, rv, rw, rx, ry, rz, sa, sb, sc, sd, se, sf, sg, sh, si, sj, sk, sl, sm, sn, so, sp, sq, sr, ss, st, su, sv, sw, sx, sy, sz, ta, tb, tc, td, te, tf, tg, th, ti, tj, tk, tl, tm, tn, to, tp, tq, tr, ts, tt, tu, tv, tw, tx, ty, tz, ua, ub, uc, ud, ue, uf, ug, uh, ui, uj, uk, ul, um, un, uo, up, uq, ur, us, ut, uu, uv, uw, ux, uy, uz, va, vb, vc, vd, ve, vf, vg, vh, vi, vj, vk, vl, vm, vn, vo, vp, vq, vr, vs, vt, vu, vv, vw, vx, vy, vz, wa, wb, wc, wd, we, wf, wg, wh, wi, wj, wk, wl, wm, wn, wo, wp, wq, wr, ws, wt, wu, wv, ww, wx, wy, wz, xa, xb, xc, xd, xe, xf, xg, xh, xi, xj, xk, xl, xm, xn, xo, xp, xq, xr, xs, xt, xu, xv, xw, xx, xy, xz, ya, yb, yc, yd, ye, yf, yg, yh, yi, yj, yk, yl, ym, yn, yo, yp, yq, yr, ys, yt, yu, yv, yw, yx, yy, yz, za, zb, zc, zd, ze, zf, zg, zh, zi, zj, zk, zl, zm, zn, zo, zp, zq, zr, zs, zt, zu, zv, zw, zx, zy, zz</sup>

Teunissen et al. *Alzheimer's Research & Therapy* (2018) 10:30  
<https://doi.org/10.1186/s13195-018-0359-x>

Alzheimer's  
Research & Therapy

REVIEW

Open Access



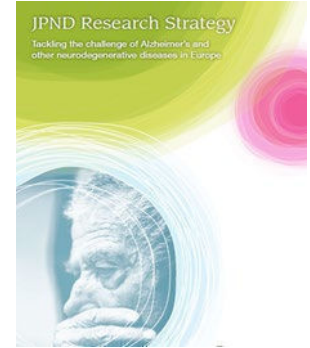
### White paper by the Society for CSF Analysis and Clinical Neurochemistry: Overcoming barriers in biomarker development and clinical translation

Charlotte E. Teunissen<sup>1\*</sup>, Markus Otto<sup>2</sup>, Sebastiaan Engelborghs<sup>3,4</sup>, Sanna-Kaisa Herukka<sup>5</sup>, Sylvain Lehmann<sup>6</sup>, Piotr Lewczuk<sup>7,8,9,10</sup>, Alberto Lleó<sup>11,12</sup>, Armand Perret-Liaudet<sup>13,14</sup>, Hayrettin Tumanli<sup>15,16</sup>, Martin R. Turner<sup>17</sup>, Marcel M. Verbeek<sup>18</sup>, Jens Wiltfang<sup>19,20,21</sup>, Henrik Zetterberg<sup>22,23,24,25</sup>, Lucilla Parnetti<sup>26</sup> and Kaj Blennow<sup>27,28</sup>



# Theme 4: Develop therapies and prevention

2013: A call for European research projects for pilot studies on preventive strategies related to Neurodegenerative Diseases

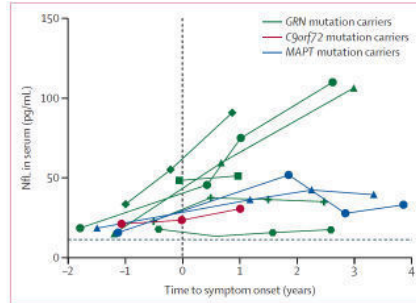
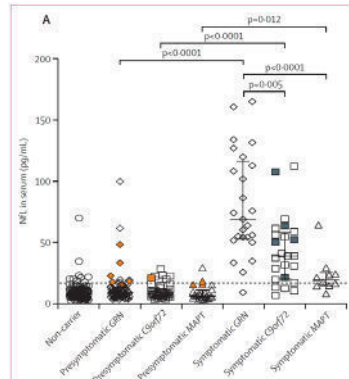


# Theme 4: Develop therapies and prevention



## PreFrontAIs

Searching for therapeutic interventions in Frontotemporal dementia with C9ORF72 repeat expansions in the presymptomatic stage



## THE LANCET Neurology

Volume 18, Issue 12, December 2019, Pages 1103-1111



### Articles

## Serum neurofilament light chain in genetic frontotemporal dementia: a longitudinal, multicentre cohort study

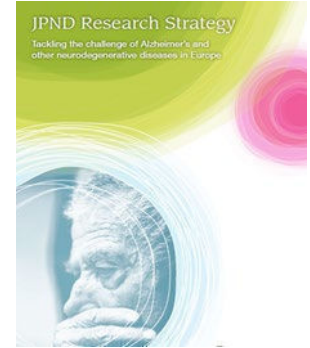
Emma L van der Ende MD<sup>a</sup>, Lieke H Meeter MD<sup>a</sup>, Jackie M Poos MSc<sup>a</sup>, Jessica L Panman MSc<sup>a, b</sup>, Lize C Jiskoot PhD<sup>a, c</sup>, Elise G P Dopper MD<sup>a</sup>, Janne M Papma PhD<sup>a</sup>, Frank Jan de Jong MD<sup>a</sup>, Inge M W Verberk MSc<sup>d</sup>, Prof Charlotte Teunissen PhD<sup>d</sup>, Prof Dimitris Rizopoulos PhD<sup>e</sup>, Carolin Heller MSc<sup>c</sup>, Rhian S Convery MSc<sup>c</sup>, Katrina M Moore BSc<sup>c</sup>, Martina Bocchetta PhD<sup>c</sup>, Mollie Neason MSc<sup>c</sup>, David M Cash PhD<sup>c</sup>, Barbara Borroni MD<sup>f</sup> ... Prof John C van Swieten MD<sup>a, g</sup> ✉



# Theme 5: Health and Social Care

2012: “European research projects for the evaluation of health care policies, strategies and interventions for Neurodegenerative Diseases”

2018 JPND call for “Multinational research projects on health and social care for neurodegenerative diseases”



# Theme 5: Health and Social Care



COORDINATOR | ROSE-MARIE DRÖES

## MEETINGDEM

Adaptive Implementation and Validation of the positively evaluated Meeting Centers Support Programme for people with dementia and their carers in Europe



Aging & Mental Health

ISSN: 1360-7863 (Print) 1364-6915 (Online) Journal homepage: <https://www.tandfonline.com/loi/camh20>

Meeting Centre Support Programme (MCSP) provides a person-centred, comprehensive and integrated programme, offering support to people with dementia and their family carers, providing information and practical, social and emotional support.

Not re-inventing the wheel: the adaptive implementation of the meeting centres support programme in four European countries

F. Mangiaracina, R. Chattat, E. Farina, F.L. Saibene, G. Gamberini, D. Brooker, S.C. Evans, S.B. Evans, D. Szcześniak, K. Urbanska, J. Rymaszewska, I. Hendriks, R.M. Dröes & F.J.M. Meiland





# The Strategic Research and Innovation Agenda – Enablers

## Enabling activities

- Research capability (fully engaging JPND MOs)
- **Supportive infrastructure / platforms (cohorts, models, imaging)**
- Industry partnership
- Regulation
- Global partnership
- **Building capacity (people)**
- Education and practitioner training
- Connection to policy makers
- Communication and outreach

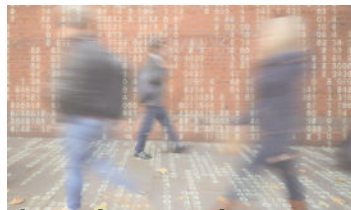


# JPND

## Major challenges for the future

### The digital transformation

- Digital Health care
- Open data access
- Artificial Intelligence / Machine Learning



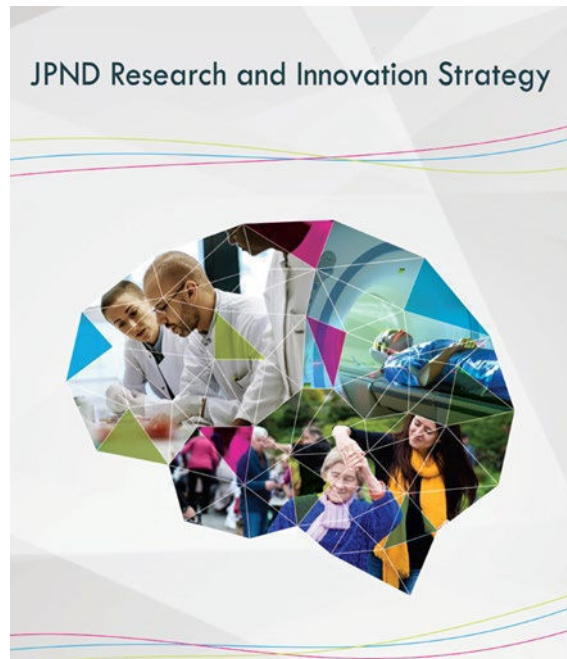
### The biological transformation

- Individualized treatments
- Genomic engineering
- Neurotechnologies



### The social transformation

- Fair access to health care



# The „JPND family“



Visit the JPND website:

- <http://www.jpnd.eu>

Sign up to the JPND News Feeds

E-mail us: [secretariat@jpnd.eu](mailto:secretariat@jpnd.eu)

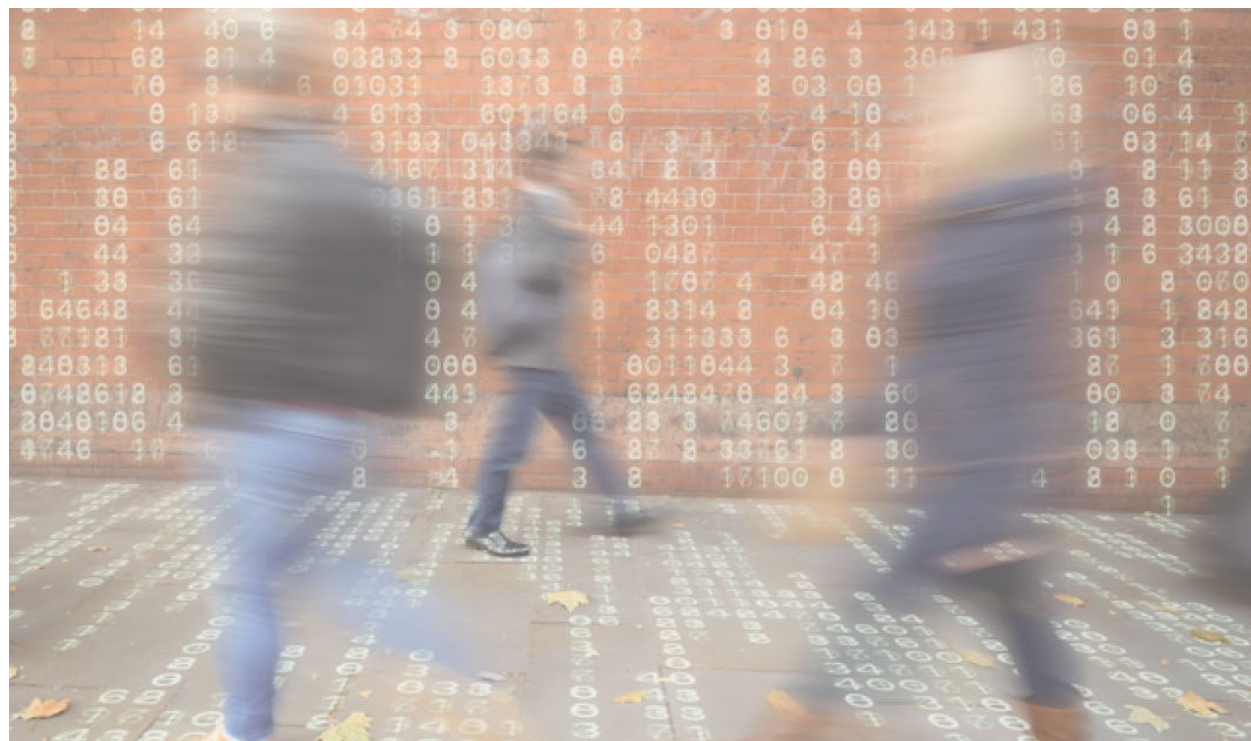


@JPNDEurope



# Thank you









# JPND Alignment Actions, working together



Alignment of  
National Strategies



Alignment of  
National Activities



Industry Partnership



Assisted Living  
Technologies



Longitudinal Cohorts



Animal and Cell  
Models



Palliative Care



Patient + Public  
Involvement



Optimisation of  
biomarkers

# Guidelines

**Font:** Arial

**Bullets:** All bullets should be black

**Colours:**

- **Cover slide**
  - Title text should be white
  - Name text should be dark blue-green
- **Content slides**
  - Header text should be dark blue-green
  - Body text should be black
- **Final slide**
  - Header text should be blue
  - Body text should be black

**Note:** Pink, lime green and light blue are no longer incorporated as text, table or bullet elements



# Keep up to date

- Visit the JPND **website**:
  - <http://www.jpnd.eu>
- E-mail us: [secretariat@jpnd.eu](mailto:secretariat@jpnd.eu)



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