

EPI-cluster

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EBRA

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Focus: epilepsy

- Many different diseases.
- Over 6 million people with epilepsy in Europe (over 60 million worldwide).
- Annual cost in Europe: over 16 billion euros.
- More than 20 “anti-epileptic” drugs, but
 - only symptomatic,
 - ineffective in >30% of the cases,
 - adverse effect.
- In addition: co-morbidities, SUDEP, stigma, access to therapy...
- EU declaration (2011) and WHO resolution (2015) on epilepsy: urge member States to improve investments in research.
- Need of trans-disciplinary, coordinated actions.

Epixchange 2018

The image shows a screenshot of a Twitter profile for @epiXchange. The profile banner features a blue background with the European Union flag and a central text box that reads "epiXchange Conference 23 May 2018, Brussels" and "A community building event for epilepsy research". Below the banner, the profile name is @epiXchange and the handle is #epiXchange2018. The profile statistics show 10.1K tweets, 4,260 following, 21.6K followers, 4,822 likes, and 13 lists. The profile is followed. A tweet from @CORDIS_EU is visible, mentioning the conference and listing several participating organizations: @desireepilepsy, @EpiCARE_ERIN, @EpiRNA, @EpiPGX, @EPISTOP, @EpiTarget, and @epiXchange2018. The tweet includes a small version of the conference banner image. The right sidebar shows "Who to follow" with accounts like MarieSkłodowskaCurie, EU Regional Policy, and EU Open Data, and "Trends for you" with #MondayMotivation.

EU Research Results (@CORDIS, X)

Twitter, Inc. (US) https://twitter.com/ 80%

Outlook AIR AIR - IMP epiXchange CMT SYMPA ASA JIRA Google Vimeo FB Live

Home Notifications Messages Search Twitter Tweet

epiXchange Conference
23 May 2018, Brussels

A community building event
for epilepsy research

@epiXchange
#epiXchange2018

Tweets 10.1K Following 4,260 Followers 21.6K Likes 4,822 Lists 13

Following

EU Research Results
@CORDIS_EU Follows you

Official CORDIS account. News and information on EU-funded research projects & results #FP7 #Horizon2020 #CORDISpacks #ibfp7 #researcheu #h2020

Luxembourg
cordis.europa.eu/home_en.html
Joined January 2010

Tweet to Message

134 Followers you know

Tweets Tweets & replies Media

Pin Tweet

EU Research Results @CORDIS_EU · 25m
Meet the 7 #EUfunded epilepsy research projects featured on our #TwitterHeader that are joining forces for the @epiXchange scientific conference on 23 May. Hosted by @desireepilepsy @EpiCARE_ERIN @EpiRNA @EpiPGX @EPISTOP, #EpiTarget and @epiXchange2018.eu

epiXchange Conference
23 May 2018, Brussels

A community building event
for epilepsy research

@epiXchange
#epiXchange2018

You, epiXchange 2018, DESIREepilepsyEU and 2 others

Who to follow · Refresh · View all

MarieSkłodowskaCurie ...
Follow

EU Regional Policy @E...
Follow

EU Open Data @EU_op...
Follow

Find people you know

Trends for you · Change

#MondayMotivation
@OfficalUoM is Tweeting about this

Diplomaten

EPI-cluster leadership

- David C. Henshall, PhD (coordinator) – Dublin, Ireland – Coordinator of EpimiRNA
- Renzo Guerrini, MD – Florence, Italy - Coordinator of Desire
- Sergiusz Jozwiak, MD – Warsaw, Poland - Coordinator of Epi-STOP
- Merab Kokaia, PhD – Lund, Sweden – Coordinator of EpiTarget
- Sanjay Sisodiya, MD, PhD – London, UK – Coordinator of Epi-PGX
- Michele Simonato, MD – Ferrara and Milan, Italy – Coordinator of EpiXchange
- J. Helen Cross, MD, PhD - London, UK – Coordinator of Epi-CARE
- Asla Pitkanen, MD, PhD – Kuopio, Finland - Past-Secretary General FENS
- Philippe Ryvlin, MD – Lausanne, Switzerland - ILAE Executive Europe
- Martin J. Brodie, MD – Glasgow, UK - President of IBE

EPI-cluster partners

- EU-funded research projects
 - Desire
 - EpimiRNA
 - EpiSTOP
 - EpiTarget
 - EpiPGX
 - EpiXchange
 - EpiCARE
- Organizations
 - International Bureau for Epilepsy (IBE)
 - International League against Epilepsy (ILAE)
 - European Alliance Epilepsy (EAE)

Synergies

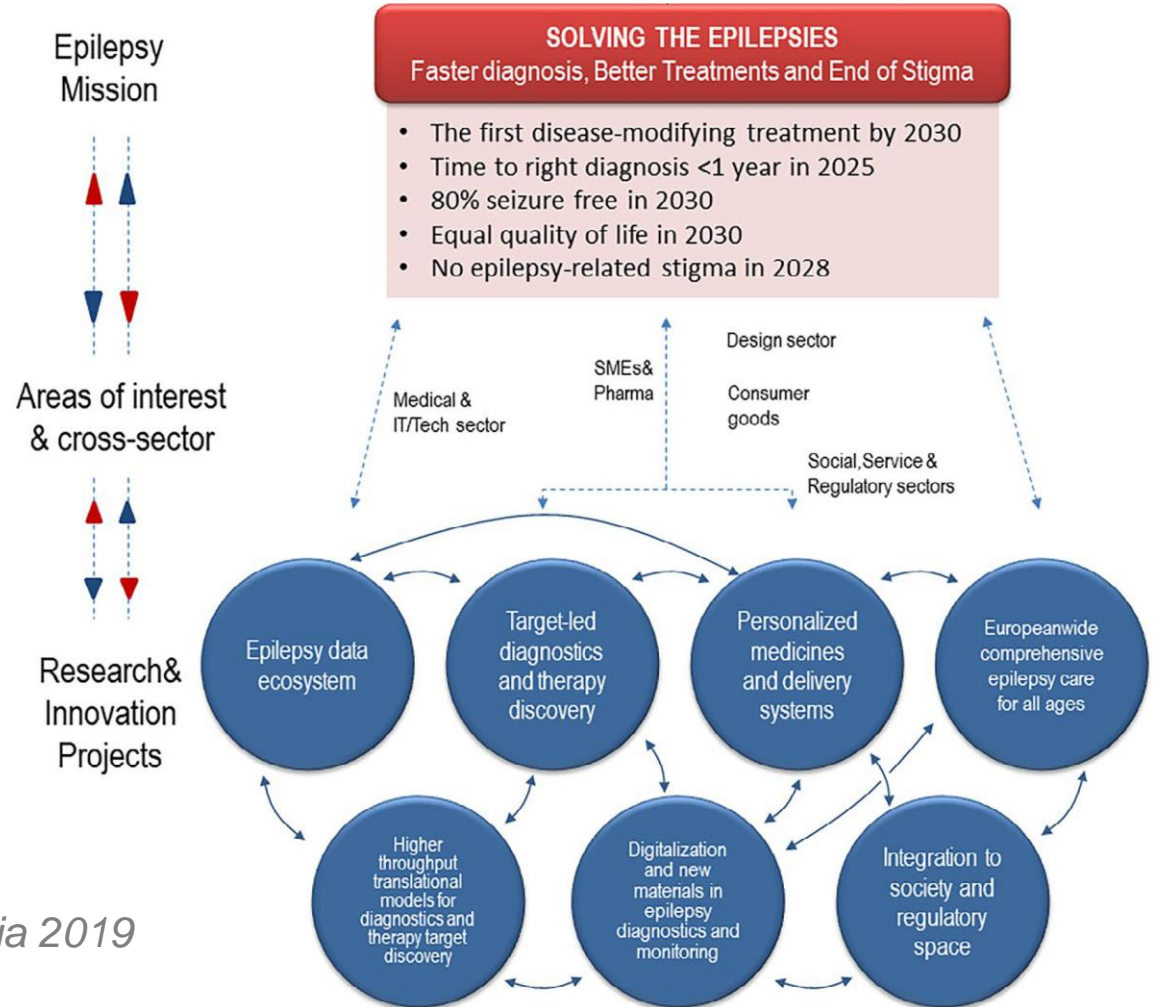
- European Science Foundation projects (Euro-EPINOMICS)
- H2020 Training networks with epilepsy focus (ECMED, EU-GliaPhD and SynaNET)
- Non-epilepsy focused European brain research projects (ERA-NET, HBP)
- Non-European research groups (CWW in the USA)

→ An existing, expanding community that will be reinforced by EBRA

Vision

- Further research and innovation efforts by this community of researchers, clinicians and industry are essential to reach tangible goals and ensure that these achievements reach persons with epilepsy.

Mission



Pitkanen et al., Epilepsia 2019

Objectives

- **Advance** the existing collaboration
- Expand the network
- Advance research on core topics
- Enhance resource-**sharing**
- Develop a preclinical trial network and enhance clinical trial structures
- Develop researcher exchange mechanisms
- Increase **engagement** of persons with epilepsy and their representatives
- Develop a global **funding** initiative on epilepsy research across agencies

Ambition

- To remove fragmentation in an underfunded area or research
- To create and maintain a **pan-European**, cutting-edge epilepsy **research platform**
- To seek and develop global **funding initiatives** in epilepsy research

Activities

- **Epi-Cluster Consensus Statement** (M6, April 2020, Brussels).
 - Goal: to bring together the leadership of Epi-Cluster with representatives of the epilepsy alliances/societies and industry, to reach consensus on working together (Epi-Area-EU).
 - 1-day; 10-20 participants.
 - Deliverables: consensus document.
- **Epi-Cluster General Conference** (M12, October 2020, Brussels).
 - Goal: (1) to discuss network priorities including the establishment of working groups and management structure; (2) to plan for a *European Epilepsy Forum*, a platform for gathering all stakeholders.
 - 2-day; 100 participants.
 - Deliverables: (1) position paper; (2) establishment of formal structures for communication and dissemination and links to external EBRA-supported brain research networks.

Activities

- **Epilepsy Sustainability and Policy Forum (M18, April 2021).**
 - Goal: to bring together key funding agencies and other stakeholders to discuss and agree approaches to secure large-scale European and potentially international funding.
 - 1-day; 40 participants.
 - Deliverables: report of the meeting.
- **Epi-Cluster Synthesis Forum (M24, October 2021).**
 - Goal: to review network achievements, operational effectiveness and future priorities.
 - 1-day; 100 participants.
 - Deliverables: white paper with final recommendations and roadmap.

Not directly supported by EBRA

- **EPI-Innovation Forum**

- Goal: to resolve issues of connecting and sharing.
- 1-day; 40 participants.
- Deliverables: publication.

- **EPI-DATA workshop**

- Goal: to foster improved awareness and know-how to exploit and commercialize research outputs from the network.
- 1-day; 40 participants.
- Deliverables: publications.



Thank You!



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