

For immediate Release



Global  
Connector  
European Connected Health Alliance

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**EURORDIS-Rare Diseases Europe and ECHAlliance partnership to foster innovation for the health and care of the 30 million patients diagnosed with a rare disease in Europe**

EURORDIS-Rare Diseases Europe and European Connected Health Alliance (ECHAlliance) announce a long-term strategic partnership to develop awareness on rare diseases, to promote initiatives aiming at accelerating innovation to improve access to information, quality diagnosis, treatment and multidisciplinary care and research for rare diseases.

EURORDIS-Rare Diseases Europe and ECHAlliance agreed on a specific joint work plan involving:

- Collaboration around the international events organized by both entities;
- Collaboration around the implementation of policy actions and writing joint policy-briefs;
- Experiences and best practices sharing across both networks and communities;
- The mutual dissemination of publications and initiatives across each network;
- The development of training courses and capacity building activities where patients can help to articulate rare disease perspectives in policies.

**Brian O'Connor**, Chair of ECHAlliance commented:

*“Our role as the Global Connector is to break down silos and*

*encourage genuine collaboration between stakeholders. There can be no more important stakeholders than citizens and patients. We want to listen to their needs and match them to solutions we see across our international network.*

*We are interested in specific actions with our partners for mutual benefit and we see this happening in this partnership”*

**Denis Costello**, Patient Engagement in Digital Technologies Senior Manager & Rare Connect Leader at EURORDIS said:

*"We are very pleased to sign a memorandum of understanding with the ECHAlliance and look forward to collaborating with them to strengthen the voice of patients at the heart of their eHealth ecosystem. We look forward to working together to articulate patients needs and the solutions that innovation in eHealth can bring through working collaboratively with all stakeholders which make up the ECHAlliance."*

### **About Rare Diseases Europe**

EURORDIS-Rare Diseases Europe is a unique, non-profit alliance of over 800 rare disease patient organisations from more than 60 countries that work together to improve the lives of the 30 million people living with a rare disease in Europe. By connecting patients, families and patient groups, as well as by bringing together all stakeholders and mobilising the rare disease community, EURORDIS strengthens the patient voice and shapes research, policies and patient services. Follow [@eurordis](#) or see the [EURORDIS Facebook page](#). For more information, visit [eurordis.org](http://eurordis.org).

### **About the European Connected Health Alliance**

The European Connected Health Alliance (ECHAlliance) is the Global Connector, facilitating multi-stakeholder connections around ecosystems, driving sustainable change and disruption in the delivery of health and social care. Our global network of Digital Health Alliances connects 78 countries and 4.4 billion people (Europe, USA, Canada, China, Africa, Asia, the Caribbean and Americas and the Pacific). Our community of over 16,500 experts - including government, health & social care providers, leading companies and start-ups, researchers, insurances, patients groups and citizens, and the investment community connect through ecosystems meetings (100+ per year), international events and our online platform, "Connector".

The Digital Health Observatory (DHO) and The Digital Health Society (DHS)

movement facilitate and promote the transfer of knowledge, experiences and best practices creating a community of knowledge in Digital health Globally.

[www.echalliance.com](http://www.echalliance.com)