Communiqué

Rare Adult Cancers Included in the Final Report of the European Parliament's Special Committee on Beating Cancer

9 December 2021, Paris – **EURORDIS-Rare Diseases Europe welcomes the European Parliament's Special Committee on Beating Cancer (BECA) decision to integrate a section on rare adult cancers – which is lacking in the Europe's Beating Cancer Plan – in their final report adopted on 9 December 2021 "*Strengthening Europe in the fight against cancer – towards a comprehensive and coordinated strategy*."**

The BECA Members of the European Parliament acknowledge that "*rare adult cancers are a public health challenge*" and support "*the introduction of a **dedicated flagship initiative on rare adult cancers** within the Europe's Beating Cancer Plan to tackle the specific challenges faced by this patient community and make the best use of the recommendations set out in the Rare Cancer Agenda 2030 to foster research and improve care in each step of the rare cancer patient journey.*"

Additionally, the BECA report, whose main theme is reducing inequalities, provides measures to foster cross-border cancer research and care, to ensure equitable access to therapies, including innovative therapies, throughout the European Union, and to promote joint health technology assessment and joint procurement of diagnostic tools and medicines.

EURORDIS and the 27 European Patient Advocacy Groups' advocates (ePAGs) across the European Reference Networks (ERNs) PaedCan, EURACAN, EuroBloodNet and GENTURIS – representing well-established international, European, and national patient organisations and covering a wide range of rare cancers – have advocated to **ensure that the challenges of the entire rare cancer patient community are integrated in the BECA report, from paediatric cancers to rare adult cancers**. United in solidarity, they also contributed to and supported Rare Cancers Europe's call to action "Rare Cancers in All Policies

> **Yann Le Cam, Chief Executive Officer of EURORDIS-Rare Diseases Europe,** said: "Ensuring that rare adult cancers as well as paediatric cancers are included in all initiatives across the four pillars of the Europe's Beating Cancer Plan is an important precondition to the European Health Union and Europe's commitment to 'leave no one behind' in health and care."

Long journey of inclusion of rare cancers in the EU political agenda

For over two decades, EURORDIS has been expressing the needs and expectations of people with rare diseases, including rare cancers, and their families. Those concerned have benefited from EURORDIS' actions in promoting policies and regulations that foster rare disease and rare cancer research and improve patient access to a timely, accurate diagnosis and adequate treatments, such as the EU Regulations on Orphan Medicinal Products, Paediatric Drugs, Advanced Therapies, the EU Directive on Cross-Border Health Care and the establishment of European Reference Networks (ERNs) for rare diseases.

Since March 2017, 24 ERNs have been launched including four ERNs relevant to rare cancers: PaedCan (paediatric cancers), EURACAN (rare adult solid cancers), EuroBloodNet (rare haematological diseases, including rare haematological cancers), and GENTURIS (genetic tumour risk syndromes).

To ensure the patient voice is heard in the ERNs, EURORDIS has created the European Patient Advocacy Groups (ePAGs). Rare cancer patient advocates in the ePAGs ensure the needs of their patient communities are integrated in the governance and development of the four above-mentioned ERNs.

Lastly, the EU Joint Action on Rare Cancers (JARC, 2016-2019) was an important milestone in the development of recommendations for rare cancers in the field of research and in the management of care throughout the patient journey. JARC brought together 60 partners from 23 European countries, including EURORDIS, the European Cancer Patient Coalition (ECPC) and Childhood Cancer International-Europe (CCI-E), and took stock of the results produced by the two EU-funded pioneering epidemiological projects on rare cancers, RARECARE and RARECARENet.

The work of the EU Joint Action on Rare Cancers led to the publication of the **Rare Cancer Agenda 2030**, a major development for the whole rare cancer community, which set out 10 main recommendations to improve rare cancer research and care through effective policies and to support the work of the European Reference Networks.

Rare Cancers in Europe

A rare cancer is defined as a cancer **affecting less than 6 per 100,000 individuals a year**. They amount to about **24% of new cancer cases per year**.

There are an estimated **5.1 million people living with a rare cancer across Europe.** In 2017, 5-year relative survival for all rare cancers was 48% compared with 63% for all common cancers. Moreover, three quarters of rare cancers have an annual incidence rate of less than 0.5 per 100,000 individuals which dramatically increases the challenge to diagnose and treat these very rare cancers (Source RARECARENet).

Although the rare disease community and the rare cancer community are sometimes regarded as two different worlds, this is far from the reality. Based on the findings of a study conducted by EURORDIS amongst 60 rare cancer patient organisations, patients and their families share the same burden and face similar challenges created by the **rarity and uncommon nature of their conditions**:

- difficulty in accessing an accurate and timely diagnosis;
- difficulty in accessing highly specialised care and adequate treatments (e.g. difficulties in finding the right specialists/medical experts and long travels to access specialised centres);
- lack of research compared to more common cancers;
- lack of registries and databases: many registries for rare diseases and rare cancers are scattered or outdated, and often lack appropriate funding;
- few clinical trials due to small patient populations.

People with rare cancers often feel **isolated and alone.** Additionally, due to the severity of rare cancers, **people living with a rare cancer can suffer greatly reduced quality of life**, and their families are also significantly impacted by the severity of the disease and the distress it causes.

List of contributing patient advocates and ePAGs

EURORDIS	
Yann Le Cam Dorica Dan	EURORDIS-Rare Diseases Europe EURORDIS-Rare Diseases Europe & Romanian Alliance for rare cancers
ERN PaedCan (paediatric cancers) ePAG advocates	
Anita Kienesberger, Anne Goeres, Lejla Kamerić, Luisa Basset	Childhood Cancer International-Europe (CCI-E)
ERN EURACAN (rare adult solid cancers) ePAG advocates	
Adela Maghear	European Cancer Patient Coalition (ECPC)
Catherine Bouvier	Neuroendocrine Cancer UK and International Neuroendocrine Cancer Alliance
Emma Kinloch	Salivary Gland Cancer UK
Eva-Maria Strömsholm	European Network of Gynaecological Cancer Advocacy Groups (ENGAGe) and Finland Gynecological cancer patients association
Iain Galloway	Melanoma Patient Network Europe Ocular/Rare
Judith Taylor	Thyroid Cancer Alliance (TCA)
Kathy Oliver	International Brain Tumour Alliance (IBTA)
Markus Wartenberg	Sarcoma Patients EuroNet (SPAEN)
Petya Zyumbileva	Melanom Info Deutschland
Roberto Persio	Associazione Italiana Laryngectomizzati (AILAR)
Teodora Kolarova	International Neuroendocrine Cancer Alliance (INCA)
Zorana Maravic, Vassiliki Fotaki	Digestive Cancers Europe (DiCE)
ERN EuroBloodNet (for rare myeloid and lymphoid cancers) ePAG advocates	
Ananda Plate	Myeloma Patients Europe (MPE)
Jan Geissler	Leukemia Patient Advocates Foundation (LePAF)
Pierre Aumont	Ensemble Leucémie, Lymphomes Espoir (ELLyE), Chronic Lymphocytic Leukemia Advocates Network (CLLAN)
Sophie Wintrich	MDS UK Patient Support Group and MDS Alliance
ERN GENTURIS (genetic tumour risk syndrome) ePAG advocates	
Claas Röhl	NF Kinder – Verein zur Förderung der Neurofibromatoseforschung Österreich and NF Patients United (NFPU)
Claudo Ales	PTEN Italia ((Italian Association for the fight against PHTS)
João de Sousa e Silva	NF Patients United (NFPU)
Nicola Reents	Familienhilfe Darmkrebs e.V. / Semi-Colon (German patient association for Lynch and Polyposis)
Rita Magenheim	Germany Li Fraumeni Syndrome
Tamara Hussong Milagre	EVITA - Portuguese Association of carriers of genetic mutations related to Hereditary Cancer
Tanja Spanic	Europa Donna Slovenia

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About EURORDIS-Rare Diseases Europe

EURORDIS-Rare Diseases Europe is a unique, non-profit alliance of 974 rare disease patient organisations from 74 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.