Press release embargo until 4pm 2nd April 2025

Today we launch a new organisation in Ireland: UCAN Ireland.

United Cancer Advocates Network is a network of advocates across the Island of Ireland. We represent a broad range of cancers and while traditionally we have been advocating in our own disease areas, now we come together to speak as one voice on key issues that impact the whole cancer community.

We launch with a focus on our most pressing issue which impacts across many cancers and that is access to cancer medications. This is an issue that has been dragging on for many years and is getting progressively worse.

We know from several reports by OECD, EFPIA and IPHA that Ireland is much slower in approval time and numbers of drugs approved for reimbursement than most of our compatriots in western Europe and indeed across Europe as a whole. For cancer medications approved by the EMA over the period 2019 to 2022 Denmark approved 36 in 134 days while Ireland approved just 14 medications in around 600 days [1].

The OECD paints a similar picture on access to medications deemed of high clinical benefit. Ireland languishes in 21st of 25th place, with access to under 40% of these high benefit medications.[2]

To make matters worse many countries also have early access schemes so patients can access medications while HTAs and negotiations on price are underway.

In Ireland patients are forced to wait. Patients die as a result of not being able to access medications. **The general public are not aware that they cannot access many lifesaving or life extending medications here.**

Many of us within UCAN have personal lived experience of this issue. Here's James Hastings, our co-chair at UCAN

'I was diagnosed with Stage 4 cholangiocarcinoma (CCA) in June 2023. I'm 42, a father of three boys, and husband to Marian.

Hearing 'Stage 4 cancer' was devastating, and being told that palliative chemotherapy was my only option felt like a death sentence. But the ***real shock*** *came when I discovered that there were immunotherapy drugs that could make all the difference—yet there was no access to them in Ireland under the HSE's reimbursement system.'*

The drug James needed for his cancer was Durvalumab, an immunotherapy available for a number of other cancers and approved for use in his cancer in December 2022 by the European medicines agency

' My oncologist even tried to secure compassionate access, but the answer was 'no.' It was heartbreaking to know that a potential lifeline existed, but I couldn't reach it.'

The current system reimbursement in Ireland is failing patients and falls well below standards in Europe. Cancer patients do not have time on their side.

'Our community rallied around us in ways I could never have imagined. People from both my local area and across the country came together, raising €300,000 to get me the treatment I needed in ***London****. Without their generosity, I wouldn't have been able to access the therapy that gave me hope and kept me fighting. It's something I will never, ever forget.'*

While we are heartened to see the key resolutions below outlined in the program for government there are no timelines for their delivery

- Investigation of early access schemes
- Review of the drugs reimbursement process
- Working to a more coordinated approach at European level
- Investment in innovative and breakthrough treatments
- Implementation of mazars recommendations

These are all initiatives we support and we want to work with Government to get clear timelines for delivery on these critical items and help support their implementation.

Reach us on

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Signed

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James Hastings Co-Chair UCAN & CCA Ireland

Niamh Conroy UCAN Secretary & Bowel Cancer Ireland

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Martin Sweeney UCAN Co-Secretary representing Prostate cancer

Cynthia Cosme Cravo UCAN member representing metastatic breast cancer

Seamus Cotter UCAN member and Chair Irish Lung Cancer Community

Siobhan Freeney UCAN member & Lobular Breast Cancer Ireland

Melody Buckley UCAN member & Ocular Melanoma Ireland

Pamela Deasy UCAN member and Pancreatic Cancer Ireland

Michael Rynne UCAN member & CLL Ireland



Bridget Carr UCAN member & Ovarian Cancer Support Ireland

1. Source: IPHA position paper on access to medications https://www.ipha.ie/wp-content/uploads/2025/02/IPHA-Position-Paper-on-Fairer-and-Faster-Access-to-Medicine.pdf
2. https://www.oecd.org/en/publications/access-to-oncology-medicines-in-eu-and-oecd-countries_c263c014-en.html