Wilms Cancer Foundation Supports the 5th IKCC Global Patient Survey on Kidney Cancer

WCF will help encourage patients, survivors and carers to share their experiences and strengthen the global evidence informing kidney cancer care

FOR IMMEDIATE RELEASE

WASHINGTON, D.C. — [Insert publication date] — The **Wilms Cancer Foundation (WCF)** is pleased to announce its participation as a Partner Organisation in the **5th International Kidney Cancer Coalition Global Patient Survey on Kidney Cancer**, launching on **World Cancer Research Day, 24 September 2026**.

The Global Patient Survey invites people diagnosed with kidney cancer, kidney cancer survivors and carers to share their experiences of diagnosis, treatment, care and life with the disease. The survey will remain open until **20 November 2026**.

As a participating Partner Organisation, WCF will help promote the survey among its international community and encourage eligible patients, survivors and carers to ensure their experiences are represented.

“Listening directly to patients, survivors and families is essential if we are to understand where kidney cancer care is working and where important gaps remain,” said **TJ Hodgkinson, Founder and CEO of the Wilms Cancer Foundation**.

“Through our participation in the fifth IKCC Global Patient Survey, the Foundation is helping ensure that the experiences of people affected by kidney cancer are heard, compared and translated into evidence that can support better information, services and care. We particularly encourage members of the childhood kidney cancer and Wilms tumor communities who are eligible to participate and contribute their perspectives.”

Understanding the Global Kidney Cancer Experience

Organised by the **International Kidney Cancer Coalition (IKCC)**, the Global Patient Survey gathers information about the experiences, priorities and unmet needs of people affected by kidney cancer in countries around the world.

The biennial survey has collected patient and carer insights since 2018. The previous survey received **2,677 responses from patients and carers across 46 countries**, making it the largest participation in the programme to date. The 2026 survey marks ten years of IKCC listening to the international kidney cancer community and developing evidence about where improvements are needed.

Survey findings can help patient organisations, healthcare professionals, researchers and policymakers:

- Identify gaps in kidney cancer diagnosis, treatment and support
- Understand differences in patient experiences between countries
- Recognise unmet physical, emotional and informational needs
- Improve communication and shared decision-making
- Establish priorities for patient advocacy and healthcare improvement
- Support research informed by real-world patient and carer experiences
- Share effective approaches across countries and healthcare systems

Why International Participation Matters

The value of the survey depends on hearing from people with different diagnoses, backgrounds and healthcare experiences across many countries.

A broad international response can reveal common challenges while also identifying important geographical differences. Comparing national findings with global averages may help patient organisations and healthcare leaders determine where local services are performing well and where additional attention or resources may be required.

When more than **100 participants from one country** complete the survey, IKCC can produce a Country-Specific Report. These reports provide more detailed findings for the participating country and can support local advocacy, programme planning and discussions with healthcare professionals and decision-makers.

WCF therefore encourages eligible participants throughout its international network to complete the survey and share it with others affected by kidney cancer.

Representing the Childhood Kidney Cancer Community

The Wilms Cancer Foundation brings a specialist childhood kidney cancer perspective to the international kidney cancer community.

Wilms tumor is the most common form of kidney cancer diagnosed in children. Although the experiences of children and families may differ from those of adults with kidney cancer, their perspectives can contribute to a more inclusive understanding of diagnosis, treatment, caregiving, survivorship and long-term support.

Through its participation, WCF aims to raise awareness of the survey among:

- People diagnosed with kidney cancer
- Kidney cancer survivors
- Parents, family members and carers
- Wilms tumor survivors who meet the survey's participation criteria
- Healthcare professionals supporting kidney cancer communities
- Patient advocates and childhood cancer organisations

This work aligns with WCF's wider commitment to ensuring that the voices of children, survivors and families inform education, advocacy, research communication and future service development.

Supporting Patients, Survivors and Carers

Patient experience data can reveal needs that may not be fully captured through clinical studies alone. Alongside questions about medical care, global patient surveys can help identify challenges involving access to information, emotional wellbeing, communication with healthcare teams, participation in treatment decisions and the wider effects of kidney cancer on everyday life.

Carers also provide an important perspective. They frequently help patients understand information, attend appointments, manage treatment, navigate healthcare services and cope with the emotional and practical consequences of cancer.

By including both patient and carer experiences, the survey can create a broader picture of how kidney cancer affects individuals and families throughout the care pathway.

WCF's Role in the Global Survey

WCF will support the survey by helping make information available through its website, digital platforms, educational network and communications channels.

The Foundation's participation will include:

- Raising awareness before and during the survey period
- Sharing survey information with patients, survivors and carers
- Encouraging engagement through social media and digital communications
- Connecting with healthcare professionals and partner organisations
- Supporting international participation across WCF's network
- Highlighting the importance of childhood kidney cancer perspectives
- Sharing relevant findings following publication of the survey results

IKCC has developed a multilingual promotional toolkit for Partner Organisations containing frequently asked questions, adaptable emails, healthcare professional engagement resources, social media materials, website copy, newsletter content and an infographic.

These resources will help participating organisations communicate consistent information while adapting their outreach to the languages and needs of their own communities.

Encouraging Healthcare Professional Engagement

Healthcare professionals are among the most effective channels for reaching patients and carers who may wish to participate.

WCF encourages doctors, nurses, allied healthcare professionals, treatment centres and survivorship services to help raise awareness by:

- Sharing the survey with eligible patients and carers
- Displaying or distributing survey information
- Including the survey in clinic communications
- Sharing survey materials through professional networks
- Encouraging colleagues to support international participation

Strong engagement from the healthcare community can help the survey reach people who may not already be connected with a patient organisation.

Turning Patient Experience into Action

Collecting information is only the beginning. The value of the Global Patient Survey lies in using its findings to identify priorities and encourage practical improvements.

WCF will review the published findings for issues relevant to people affected by Wilms tumor and other childhood kidney cancers. Where appropriate, the Foundation will use those insights to help inform its educational resources, advocacy, international partnerships and patient-support initiatives.

This work complements WCF programmes including the **Global Wilms Tumor Initiative™**, **Wilms Tumor Knowledge Index™**, **Global Educational Library**, **Wilms Tumor WebApp** and international healthcare professional engagement.

How to Participate

The 5th IKCC Global Patient Survey on Kidney Cancer will:

- **Launch:** 24 September 2026
- **Close:** 20 November 2026
- **Participants:** Eligible kidney cancer patients, survivors and carers
- **Format:** International patient-experience survey

WCF will publish the official survey link and participation information when the survey opens. Participation is voluntary. Individual responses contribute to a wider international understanding of the needs, priorities and experiences of people affected by kidney cancer.

About the Wilms Cancer Foundation

The **Wilms Cancer Foundation (WCF)** is an international childhood cancer charity dedicated exclusively to improving outcomes for children affected by Wilms tumor through education, awareness, advocacy, research collaboration, innovation, and patient support. As an official partner supporting the **World Health Organization's Global Initiative for Childhood Cancer (GICC)**, the Foundation works with hospitals, healthcare professionals, researchers, governments, and patient organizations worldwide to strengthen care, improve access to trusted information, and promote earlier diagnosis and better outcomes for children affected by Wilms tumor.

Through the **Global Wilms Tumor Initiative™** and its international programmes, the Foundation works to expand access to trusted information, strengthen patient and caregiver education, support healthcare professional engagement and address inequalities in childhood kidney cancer outcomes worldwide.

Website: www.WilmsFoundation.org

About the International Kidney Cancer Coalition

The **International Kidney Cancer Coalition** is an independent international network of patient organisations that focus exclusively on kidney cancer or include kidney cancer as an area of their work. IKCC brings together patient organisations from around the world to share knowledge, amplify patient voices and improve the lives of people affected by kidney cancer. Its Global Patient Survey identifies patient and carer experiences, unmet needs and differences between countries to inform advocacy, research and improvements in care.

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