FOR IMMEDIATE RELEASE

Wilms Cancer Foundation Calls on Childhood Kidney Cancer Community to Participate in 2026–2027 Global Patient Survey

International Kidney Cancer Coalition's landmark survey marks a decade of patient experience research, offering Wilms tumor patients, survivors and caregivers an opportunity to help shape the future of kidney cancer care, education and advocacy.

WASHINGTON, DC – October 21, 2026 The Wilms Cancer Foundation (WCF), an international charitable organisation dedicated to improving outcomes for children affected by Wilms tumor and other childhood kidney cancers, is encouraging patients, survivors, parents and caregivers worldwide to participate in the **2026–2027 International Kidney Cancer Coalition (IKCC) Global Patient Survey (GPS)**.

The international survey, which opened on 24 September 2026 and closes on **20 November 2026**, seeks to better understand the experiences of people affected by kidney cancer, identify unmet needs and highlight opportunities to improve access to care, quality of life, shared decision-making and participation in clinical trials.

The 2026–2027 survey marks 10 years of IKCC collecting patient experience data, providing an important opportunity to examine changes in patient needs and experiences over the past decade.

The Wilms Cancer Foundation is particularly encouraging members of the childhood kidney cancer community to participate, helping ensure that their experiences and perspectives contribute to the broader international understanding of kidney cancer.

Ensuring Childhood Kidney Cancer Voices Are Heard

Wilms tumor, also known as nephroblastoma, is the most common form of kidney cancer in children. Although it differs significantly from the kidney cancers most frequently diagnosed in adults, patients and families affected by childhood kidney cancer can encounter many of the same challenges involving access to care, communication, treatment decisions and long-term quality of life.

For parents and caregivers, navigating a childhood kidney cancer diagnosis can involve complex medical decisions, significant emotional and practical pressures, and challenges accessing specialist healthcare services.

Childhood cancer survivors may also face long-term health considerations, including ongoing surveillance, treatment-related complications and the transition from paediatric to adult healthcare services.

The Wilms Cancer Foundation believes that ensuring the experiences of childhood kidney cancer patients and families are represented in international patient research is important to developing a more comprehensive understanding of the needs of the wider kidney cancer community.

By encouraging participation in the IKCC Global Patient Survey, the Foundation hopes to help strengthen awareness of the challenges facing families affected by Wilms tumor and other paediatric renal cancers.

Understanding Patient Experiences and Unmet Needs

The Global Patient Survey is designed to collect information about the experiences of people living with kidney cancer and those who care for them.

Key areas explored by the survey include:

- **Access to care:** Understanding challenges and differences in accessing appropriate healthcare services, treatment and specialist support.
- **Quality of life:** Exploring the physical, emotional and practical impact of kidney cancer on patients and caregivers.
- **Shared decision-making:** Examining how patients and families participate in decisions about treatment and care.
- **Clinical trial participation:** Identifying experiences, opportunities and barriers relating to involvement in clinical research.
- **Unmet needs:** Highlighting areas where additional information, services, advocacy or patient support may be required.

The information collected will help identify best practices and opportunities to improve patient-centred care internationally.

Ten Years of International Patient Experience Research

The 2026–2027 Global Patient Survey represents a significant milestone for the International Kidney Cancer Coalition, marking a decade of collecting information about the experiences of people affected by kidney cancer.

The accumulation of patient experience data over this period provides an opportunity to examine trends, identify persistent challenges and assess progress in addressing the needs of kidney cancer patients and caregivers.

Following the survey's closure on 20 November 2026, IKCC will analyse the responses and publish reports in 2027.

These reports will examine international trends, common themes, geographical differences and progress towards reducing the burden of kidney cancer.

Country-specific reports will also be produced where more than 100 participants from an individual country complete the survey.

The findings are intended to inform future patient advocacy, education, support programmes and initiatives designed to improve kidney cancer care.

Supporting the Global Wilms Tumor Initiative™

The Wilms Cancer Foundation's encouragement of participation in the IKCC survey aligns with the objectives of its **Global Wilms Tumor Initiative™ (GWTI)**, an international programme focused on improving childhood kidney cancer awareness, education, advocacy and support.

Through the GWTI, the Foundation is working to address disparities in childhood kidney cancer care, strengthen access to educational resources and support collaboration between families, healthcare professionals, researchers and international organisations.

Understanding patient and caregiver experiences is an important component of these objectives.

The Foundation recognises the value of international patient surveys in identifying gaps in healthcare provision and highlighting areas where education, support services and advocacy may be strengthened.

The IKCC survey offers an opportunity for eligible members of the childhood kidney cancer community to contribute their experiences to a wider international research initiative.

Encouraging Participation from Patients, Survivors and Caregivers

Commenting on the survey, **TJ Hodgkinson, Founder and Chief Executive Officer of the Wilms Cancer Foundation**, said:

"Patients and families affected by childhood kidney cancer have experiences and challenges that deserve to be heard and understood.

"While Wilms tumor is primarily a childhood cancer, the experiences of parents, caregivers and survivors are an important part of the wider kidney cancer conversation.

"The International Kidney Cancer Coalition's Global Patient Survey provides an opportunity for people affected by kidney cancer to share their experiences and contribute to a better understanding of the challenges patients and families face.

"We are encouraging members of the Wilms tumor and childhood kidney cancer community to consider participating in this important international initiative.

"By sharing their experiences, patients and caregivers can help identify unmet needs, strengthen patient advocacy and contribute to efforts to improve the quality of care and support available to people affected by kidney cancer worldwide."

How to Participate in the Global Patient Survey

The 2026–2027 IKCC Global Patient Survey is open to individuals with lived experience of kidney cancer, including people who have received a kidney cancer diagnosis and those who have cared for someone affected by the disease.

Individuals who participated in previous surveys are also invited to take part again.

Survey details:

- **Organiser:** International Kidney Cancer Coalition (IKCC)
- **Survey:** 2026–2027 Global Patient Survey on Kidney Cancer
- **Opened:** 24 September 2026
- **Closing date:** 20 November 2026
- **Time required:** Approximately 15 minutes
- **Eligibility:** People with lived experience of kidney cancer, including patients and caregivers

Complete the survey here:

https://picker.fra1.qualtrics.com/jfe/form/SV_3E2boBLYUpNYRvM

The Wilms Cancer Foundation encourages eligible members of its international community to participate before the 20 November deadline and to share the survey with other patients, survivors and caregivers who may wish to contribute.

Strengthening the Patient Voice in Global Kidney Cancer Care

The Wilms Cancer Foundation believes that patient and caregiver experiences should play an important role in shaping future healthcare education, advocacy and support services.

International initiatives such as the IKCC Global Patient Survey can help provide valuable insight into the challenges experienced by people affected by kidney cancer across different healthcare systems and geographical regions.

By encouraging participation from the childhood kidney cancer community, the Foundation hopes to contribute to a broader and more inclusive understanding of patient needs while supporting international efforts to improve kidney cancer care.

About the International Kidney Cancer Coalition

The International Kidney Cancer Coalition (IKCC) is a global alliance of patient organisations working to reduce the burden of kidney cancer worldwide.

Through international collaboration, patient advocacy, education and research into patient experiences, IKCC works to strengthen the patient voice and promote improvements in kidney cancer care.

Website: www.ikcc.org

About the Wilms Cancer Foundation

The **Wilms Cancer Foundation** is an international childhood kidney cancer organisation dedicated to improving awareness, education, support, research communication and global collaboration for children and families affected by Wilms tumor. Through the **Global Wilms Tumor Initiative™** and its international programmes, WCF 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**

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